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PRINCIPAL INVESTIGATOR: Doctor Mary P. Williams

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14. ABSTRACT <p>The Breast Health Belief Systems Study was designed to test the saliency of integrating elements of study participants' belief system about breast cancer to increase early breast cancer screening practices. The study targeted African American women living in rural Georgia. The study consisted of three phases: One - an ethnographic survey to determine the scope and depth of beliefs and practices regarding breast cancer; Two used the data gathered from phase one to develop an interpersonal, target-specific breast health promotion program, and Three - implementation and measuring the effectiveness of the intervention and its delivery strategies. Women indigenous to the study sites were trained as lay health workers to assist with participant recruitment and the delivery of the intervention. Sixty-four women 40-60+ participated in the ethnographic survey. Three hundred and twenty participated in the intervention phase. Findings from this study, while not conclusive, supported the primary hypothesis and demonstrated the need for: health promotional messages to be structured within the cultural and social support systems of low-income rural African American women; and the need for transmission to medical providers of the significance of beliefs on health practices.</p> <p>Collaborators in this study included Georgia State, Albany State, Fort Valley State, and Savannah State Universities, and the Older Americans Council of Middle Georgia.</p>				
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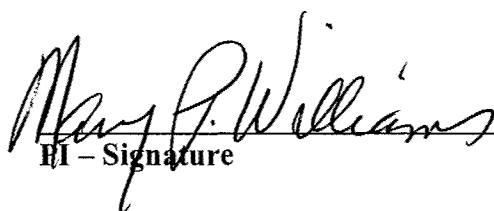
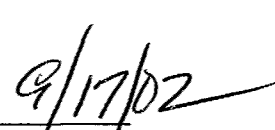
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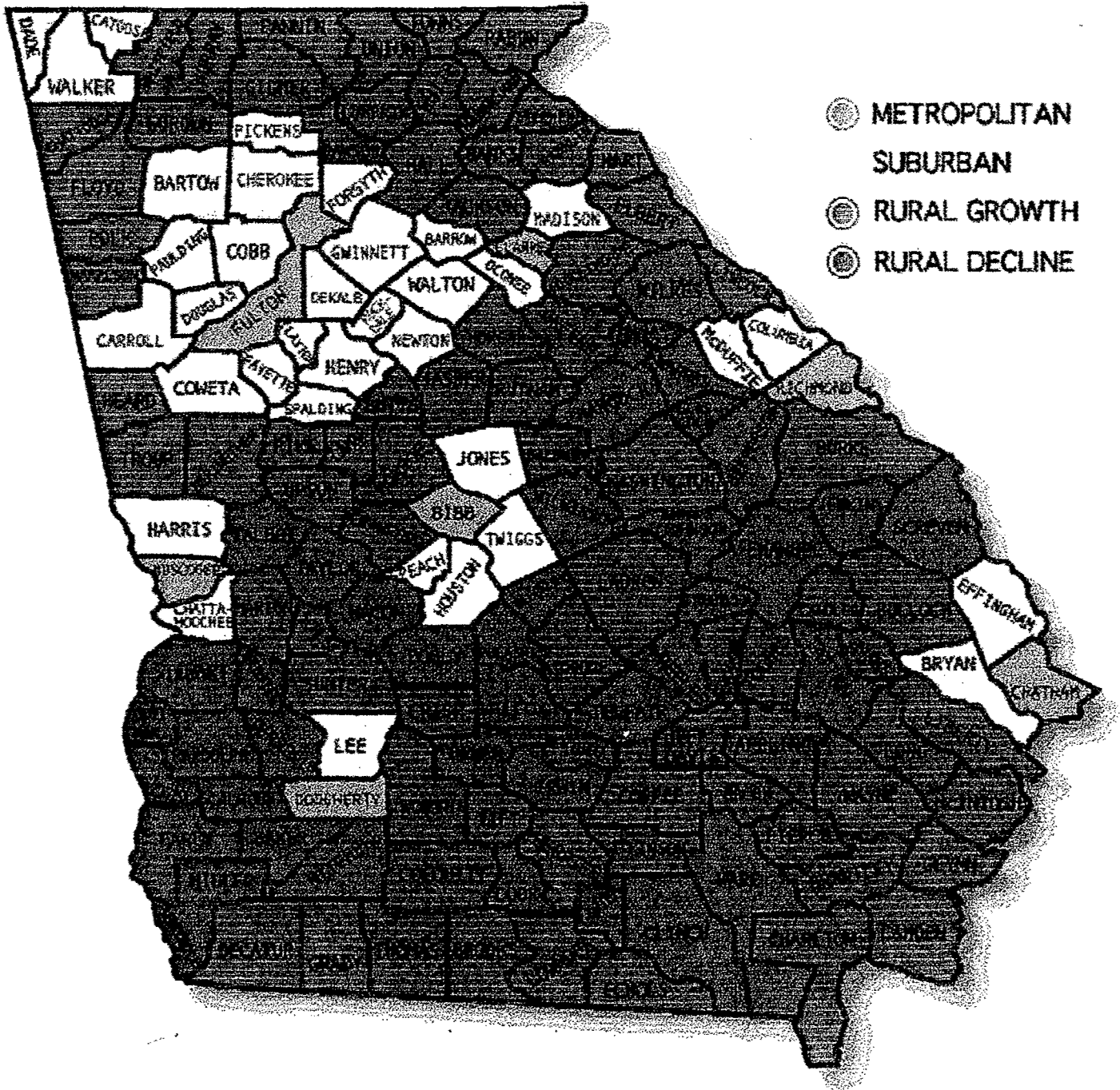
INTRODUCTION

This report describes the development and implementation strategies of the Breast Health Belief Systems study. Conducted by the Morehouse School of Medicine, Atlanta, Georgia, and the study test the saliency of integrating the belief systems of rural African American women into the design of an interpersonal breast health intervention. The primary premise of the study was that a breast health promotion approach that proceeds from, and responds to specific belief systems among low-SES, African American, rural populations will motivate increased compliance to recommended cancer screening schedules, and positive shifts in knowledge and attitudes. This research proceeded in three phases: (1) an in-dept qualitative analysis of intra cultural variations in knowledge, attitudes, and beliefs regarding breast disease in low-SES African American women. (2) use of these ethnographic data to develop an intervention for interpersonal delivery of breast health information to breast disease free women and (3) measurement of the effectiveness of an educational approach that uses lay workers indigenous to the target communities. Sixty-four women participated in the phase one and 320 in phase 3. The research targeted select rural Georgia counties. As the map on the following pages shows, many of Georgia's southern counties are in economic decline. Collaborators are Georgia State University, Fort Valley State University, Albany State University, and Savannah State University. Faculty and students working with the study represented the disciplines of anthropology, sociology, social work, and nursing.

Georgia

facts and figures

The Four Georgias



The University of Georgia College of Family and Consumer Sciences

BODY

Background

Death rates are far too high from diseases that are preventable or, if contracted, have a high probability of being cured if detected during early stages of development. Breast cancer is one of those diseases (1,2). It is the most common cancer in American women: one in every 10 women will develop breast cancer sometime in her lifetime (3). While research findings and Professional organizations support regular breast examination and mammography as effective screening methods for early stage breast cancer (4,5), 44 percent of white women, 51 percent of Hispanic, 52 percent African American, and 54 percent of Asian American reported not having a mammogram in the past two years. The highest death rate from breast cancer was reported among African American women (6). This higher mortality rate is thought to be due largely to late stage diagnosis. While reasons are suggested for this phenomenon, e.g., lack of knowledge, failure of health provider to initiate screening procedures, costs, culturally inappropriate approaches (7,8), empirical research is limited.

It is well documented by previous research that African American women as a whole present to the medical community in more advanced stages of breast cancer than white women. While the incidence of breast cancer is higher in white women the overall mortality rates from breast cancer is higher in African American women. This higher mortality rate is thought to be due to late stage diagnosis and socioeconomic status. Despite the documentation of the higher morbidity and mortality of breast cancer among African American women, there is limited information published on effective interventions to increase breast cancer screening among this population. Women of color are members of heterogeneous groups. Generalizations that create health profiles for women of color are dangerous because exceptions to the rules are numerous (9). However, relatively little research has been devoted to identifying effective strategies for increasing breast cancer screening rates among African American women of varying cultural and intra cultural backgrounds. Social scientists and health communications researchers have held that if health promotion campaigns are to influence the audience as intended, they must be culturally, demographically, and geographically appropriate (10,11,12). Research defining the variable of cultural sensitivity is also very limited regarding interventions that target diverse populations.

Research examining the efficacy of health promotion appeals, content, and channels of delivery regarding breast cancer has also been very limited in public health research. A number of factors frustrate the formulation of effective campaigns to promote healthy behaviors and practices. First, health promotion campaigns usually exhort people to change deeply rooted beliefs and behaviors that have been continually reinforced over a lifetime, and perhaps throughout preceding generations. Secondly, health promotion information and recommendations are traditionally based upon epidemiological findings that do not often include a broad, in-depth assessment of culturally driven behaviors that are especially prevalent in multiethnic and multi cultural societies. Further, virtually all health promotion message approaches are based on cognitive/behavioral theories of communication that assume that all people view and interpret situations similarly (12,13,14). However, health and disease may mean different things to different people. McLeroy (11) and colleagues have suggested extension of the traditional

cognitive framework to include interpersonal processes, institutional factors, community factors, and public policy issues as well.

Around the world, health promotion interventions are using strategies involving community health worker or lay advisor (helping healers) programs to reach traditionally underserved populations (15,16,17). The difference between these programs can be explained on a continuum of formal to informal helping (18). The formal end of the continuum consists of the paraprofessional/outreach worker who is a paid employee of some community-based agency or organization. The informal end of the continuum is that community person who always seems to be they're volunteering to help individuals and community efforts. Both of these strategies involve identifying individuals within existing social networks of the targeted audience, who other network members trust and regularly turn for social support. While several studies report the effectiveness of the informal model of this type worker to deliver breast health messages, particularly in rural areas, few reports evaluate the impact of utilizing the formal model for such activities

Relatively little research has been devoted to identifying effective strategies for increasing breast cancer screening rates among low-SES and black women of varying cultural and intracultural orientations. Black and white women across all ethnicities and socioeconomic strata are regularly exposed to health-related messages through the mass media and the work of public agencies and nonprofit organizations. Acceptance of recommendations, however, remains inconsistent.

Research examining the efficacy of health promotion appeals, content, and channels of delivery has also been very limited in public health research. Social scientists and health promotions professionals have maintained that if health promotion campaigns are to influence the audience as intended, they must be culturally, demographically, and geographically appropriate. Research examining the defining variables of cultural sensitivity are likewise very limited regarding health promotion efforts particularly those targeting culturally diverse audiences.

Despite this higher mortality rate of breast cancer among African American women, there is limited information published on effective interventions to increase breast cancer awareness and early screening. Research examining the efficacy of health promotion message appeals, content, and channels of delivery has also been very limited in public health research. These research areas as well as those examining the defining variables of cultural sensitivity are almost completely unexplored regarding health promotion efforts specifically targeting low-SES and African American audiences.

For the purposes of this research, culture is defined as a set of interlocking cognitive schemata that constructs and gives meaning to what people do in their everyday lives. In order to understand how culture works, it is necessary to examine the storage and transmission of information and belief systems shared by a group of people. These strategies are used to guide health-seeking behavior and give it meaning to people's lives. Beliefs are defined as the basic units of thought that establish a relationship between at least two entities. Cognitive beliefs assess the truthfulness or falsify of a given topic. Verbal beliefs are called opinions. Values are beliefs that attempt to determine worth by assigning the moral dimensions of good or bad, right or wrong. Attitudes are a set of beliefs that predispose people to react positively or negatively.

They include components of cognition, affect, and intensity. Beliefs that are primitive and rigid in one culture often change in another, and values can change within a cultural over time. Most importantly, beliefs, values, and attitudes are culturally driven. Help-seeking behaviors are, in effect reenactment of cultural models of the social world. Consequently, belief systems from help seeking options and the individual and group evaluation of these options. It should be noted that cultural knowledge is not shared equally throughout a group, and members use diverse sources for their knowledge.

Preliminary findings on breast cancer from previous Morehouse sponsored studies suggest that blacks do not participate in early detection for cancer, even in areas where tests are low costs or free. Only 30% of inner city and 20% of rural women were likely to receive regular screening for breast cancer; rural, particularly coastal, study subjects rely heavily on religious beliefs and folk medicine. Thirty-six percent of those surveyed did not feel the urgency to get mammograms or pap smears on a regular bases; educational interventions that utilized lay health workers to conduct in-home education to increase adherence among low-income, inner city and rural women demonstrated a significant impact in increasing rate of breast cancer screening. The success of these studies was useful in designing the strategies for the proposed research. These results suggested the need for additional attention to the screening, knowledge, access and beliefs and behaviors from intracultural perspectives among the black population. Using our considerable experience in health promotion efforts among minority and disadvantaged populations combined with the expertise and experience of medical anthropologists from two major universities, this study sought to expand the knowledge base on this matter.

Hypothesis- A breast health promotion approach that proceeds from, and responds to specific belief systems among low-SES, African American, rural populations will motivate increased compliance to recommended cancer screening schedules, and positive shifts in knowledge and attitudes. This hypothesis incorporates the following sub-hypotheses:

Qualitatively, the proposed research hypothesized the following findings:

1. The more closed a cultural system is the less likely individuals who live within that system is to seek preventive biomedical care.
2. The more frequently members of rural communities participate in complex, urban systems, the more likely they are to seek preventive, biomedical care.
3. Culturally based belief systems regarding preventive, biomedical care are stronger persuasive agents than access to, or affordability of preventive care.

From a quantitative perspective, the hypothesis incorporates the following sub-hypotheses:

4. Knowledge of breast cancer risks and prevention among women aged 40-65 will increase by approximately 30%.
5. At follow-up, the percentage of women aged 40-65 who have had a clinical breast examination within the past year will increase by at least 20%.

6. At follow-up, the percentage of women aged 40-65 who have had a mammogram within the past year will increase by at least 20% and will be at least 50%.

Procedures:

Specific Aims. The GOAL of the Morehouse School of Medicine Breast Health Belief System Study was to reduce the incidence of breast cancer and promote breast health seeking behaviors among low-SES, medically underserved, African American, rural populations. Positioned within three, uniquely distinct communities in rural Georgia, this project aimed:

- (1) To qualitatively determine intracultural variations in the variety, scope, and depth of belief systems regarding breast disease among low-SES, rural African American women who have received a diagnosis of breast cancer;
- (2) Using the ethnographic data gathered, to conduct a demonstration project involving delivery of breast health information based on the belief systems of low-SES, culturally diverse African American populations on an interpersonal level;
- (3) To create and train an ongoing network of breast health information providers among individuals who have already gained access to and credibility with the target rural communities.

This study was operationalized in accordance with the following **Technical objectives:** The proposed study includes both qualitative and quantitative dimensions. Specific technical objectives include:

Ethnographic Assessment

Objective 1: Operationalize ethnographic assessment of belief systems.

Sub-Objective 1.1: Recruit and train the interviewers (research assistants) for the qualitative component of the study.

Sub-Objective 1.2: Recruit study participants.

Sub-Objective 1.3: Conduct the ethnographic assessment of belief systems.

Sub-Objective 1.4: Analyze data.

Objective 2: Develop breast health information based on ethnographic analysis of the belief systems of the target population.

Sub-Objective 2.1 Using qualitative data formulate an interpersonal educational message.

Sub-Objective 2.2: Structure the message for diffusion.

Objective 3: Develop the intervention delivery system.

Sub-Objective 3.1: Develop curriculum and conduct training workshop for lay health workers.

Sub-Objective 3.2 Develop primary/secondary support systems.

Sub-Objective 3.3 Recruit study sample.

Sub-Objective 3.4 Conduct Intervention.

Sub-Objective 3.5 Track productivity of lay health workers.

Objective 4: Evaluate the impact of the comprehensive intervention on breast cancer screening knowledge, attitudes, and practices by measuring these parameters at baseline, and following the intervention.

Results and Discussion:

Unanticipated operational challenges:

- ☐ We did not anticipate the difficulties we encountered in participant recruitment.
- ☐ Failure of health worker in one site to recruit
- ☐ Scheduling difficulties
- ☐ Logistic issues

All of these issues are discussed within the Statement of work.

STATEMENT OF WORK

(Because problems described within the statement of work activities, the work schedule was revised upon approval and extended 6 months)

Ethnographic Assessment

Months

1 - 2	Recruitment of research assistants (interviewers)
3 - 6	Review of Surveillance, Epidemiology, and End Result (SEER) Program data Recruit lay health workers (CEPAs) Using SEER data and lay health workers as liaisons identify and recruit study participants
7	Research assistant (interviewer) training Development of question schedules
8 - 12	Interviewing/data gathering
13 -14	Data coding and analysis

Message Development

- 15 - 16 Review ethnographic data
Specify message components according to the PHM framework
- 17 - 18 Identify mammography and clinical breast exam sites
Develop diffusion strategy

Intervention

- 19 - 20 Develop curriculum components for lay health worker intervention training
- 21 - 22 Develop primary/secondary support systems in each site
Conduct training workshop for lay health workers

Pre-test message and delivery
- 23 - 24 Recruit intervention study participants
Carry out random assignment to intervention or control groups
- 32 - 37 Conduct intervention
- 38 - 39 Implement 6-month follow-up of intervention group
Provide control group education
- 40 - 42 Analyze data and evaluate project
Write reports

Target Areas. The research was conducted in rural counties in South Georgia where similar and distinctly different demographic characteristics existed. These counties generally rank lower than their urban counterparts on conventionally used, measurable indices of quality of life, i.e., poverty, low population density, large geographic expanses, lack of human service-related resources and negative capital flow to urban areas.

Procedures:

The study consists of three Phases: One - An ethnographic survey of women who have or have had breast cancer to determine intra-cultural variations in the variety, scope and depth of beliefs and practices (before and after diagnosis/treatment) regarding breast cancer;

Two - Use of the analysis of data gathered from Phase One to develop an interpersonal, target-specific breast health promotion program for women with no known breast cancer and who have not had a mammogram in the twelve months preceding participation in the study; and, finally,

Phase Three - implementing and measuring the effectiveness of the breast health intervention and its delivery strategies.

Our Breast Health Belief Systems Study involves researchers, community members, and practitioners in a joint process aimed at meeting both research and intervention objections. This process bares similarities to the Participatory Action Research approach (PAR)(25) and the Braithwaite-Lythcott (26) model of community organization for health promotion. Both allow the insiders view of life to be considered in health education

program' planning. Adapting elements from these approaches, this project involves the use of two research components: a single case study design in Phase One (ethnographic survey) which allows for an empirical investigation of a contemporary phenomenon (underutilization of breast cancer screening methods by African American women) within its real-life context and from the perspective of the effected group; and a quasi-experimental design in Phase Three (the intervention) utilizing qualitative and quantitative methods. Establishing the Research Team: Investigators for this study include a gerontologist/clinician, a medical anthropologist, a health communications specialist, and a biostatistician.

History and Context of Rural Georgia: The BHBS study took place in middle and southern Georgia in 13 counties in Phase One and three (3) counties in Phase Three. Most of these counties generally rank lower than their urban counterparts on conventionally used, measurable indices of quality of life, i.e., poverty, low population density, large geographic expanses, lack of human service-related resources and negative capital flow to urban areas. Our research objectives dictated that these counties fall within at least one of three categories: an physically isolated area of extreme poverty, a rural area that provides access to a metropolitan center, and a poor coastal area that feature a wide range of intra-cultural variations including one with potential Gullah (practice of traditional West African folkways) influences. In Phase One the thirteen counties are reported in geographic groupings or public health districts: **Albany for the southwest, Macon for middle Georgia, and Savannah for the southeastern and coastal regions.** The African American population in these counties is 40 percent or greater. All three of these areas contain counties, which fall into at least one of our site categories. The Savannah district is the site where more small pockets of residents practice of West African folkways. Because of demographic characteristics, it was assumed that these three geographical sites would provide variation in the samples for exploring the study's assumptions.

Each of these regions contained a historically black college or university (HBCUs) from which graduate level research assistants were selected and trained to conduct the ethnographic interviews. These HBCUs were Albany State University located in the southwest region, Fort Valley State University located in middle region, and Savannah State University located in the southeastern coastal region. Study subjects were recruited from counties within these three sites. As a convenience for data management these sites were named for the HBCU in their region and are referred to by those names throughout the study report. Counties selected for study recruitment were assigned to one of the following site groups: poor and isolated (50 miles or more from a major urban area), poor but located near (within 25 miles of a major urban area), and poor and coastal with a significant cultural variation in population and where traditional African customs are actively practiced. Figure 2 depicts these study sites. Table 1 shows the demographic characteristics of the targeted counties in these sites, and Table 2 the demographics of the women participating in the ethnographic survey.

In order to facilitate the implementation of this study, three historically black colleges and universities (HBCUs) in the study areas are partners. Senior or graduate students from these schools were trained by our anthropologist, in anthropological methods of data collection and management and utilized as research assistants. Major criteria for selection of the research assistants were that they live in or near one of the study communities, have a history of regular involvement in local community-based events, and a demonstrated interest in community welfare. A faculty preceptor from each school assumed the responsibility for selecting students and the on-site supervision of the student research assistants. Both students and preceptor received nominal financial compensation for their efforts. These criteria provided a number of advantages: cultural and geographic familiarity, inter-institutional collaboration, and cost effectiveness in terms of controlling travel expenses in connection with the ethnographic analysis. Lay health workers, trained on how to recruit study participants, assisted in Phases' One and Two to assist with pilot-testing the instruments and recruitment of study participants, and in Phase Three with recruitment and delivery of the educational intervention.

Unique to this research team was the Cooperative Extension Service. Though better known for its agricultural focus, the extension service also includes community development programs including health education. The Cooperative Extension Service, like the health department, has staff in all 129 counties in the state of Georgia.

One of our HBCU partners, Fort Valley State University Extension Program, operates in 13 rural counties in Georgia and is a longstanding trusted institution among the black community. The Fort Valley Program employs paraprofessionals called Cooperative Extension Program assistants (CEPA) who are usually indigenous to the community in which they work. Supervised by home economist, their responsibilities include in-home economic and health education activities. CEPAs functioned as formal lay health workers in this study.

Ethnographic Assessment

Phase One: Ethnographic Survey: Hypotheses: Three assumptions guided the selection of research sites and the collection of ethnographic data. They were 1). Women from isolated rural communities are less likely to seek preventive biomedical care; 2). Women from rural communities with access to complex urban systems are more likely to seek preventive biomedical care; and 3). Cultural beliefs about preventive cares for breast cancer and for health problems in general are stronger persuasive agents than access to, or afford ability of medical care services.

OBJECTIVE 1: Operationalize ethnographic assessment of belief systems.

Cultural knowledge or belief structures of rural residents provide a schema for the storage of information about breast cancer and a logic for solving problems that arise from the disease. They are taken-for-granted models of the world that are widely shared by members of a group. They play an enormous role in people's understanding of the world and their behavior in it. Consequently, they motivate behavior and provide a directive force in daily life. However, cultural knowledge is not shared equally throughout a group, and members use diverse sources for their knowledge. For example, Mathews et.al. found that African American women in rural North Carolina draw on multiple sources of knowledge in order to come to terms with their breast cancer.¹ Delineating variations in beliefs is an important design element to more effective intervention strategies.

Since beliefs about breast cancer are a product of both personal experiences and information obtained through interactions with others (either interpersonally or through media), not all members of a group will have identical sets of cultural knowledge. Rather some variation from a prototypical cultural model is expected.² Acting on knowledge entails the operationalization of beliefs. Help seeking behavior are shaped by culturally distinctive illness beliefs.³ Action presupposes an individual's or group's judgment about their expertise or competency in their system of shared cultural knowledge. Help seeking behaviors (or lack of them) in response to breast cancer are reenactments of their cultural models of their social world. Consequently, beliefs frame their help seeking options and their evaluation of these options.

Belief systems and their variations of the three populations were qualitatively analyzed by using a set of data collection and analysis techniques grounded in symbolic and cognitive anthropology that assumes that people's behavior is guided by their interpretations of, and beliefs about breast cancer. Illness explanatory models (EMs) of an individual or group effectively determine the etiology, symptomatology, treatment options and use of health care providers. Beliefs are located in people's local worlds. They provide a person having breast cancer with a causal explanation for the disease. They also mediate the recognition and interpretation of symptoms. Local experiences mediate the number and types of options people perceive as feasible for treating their disease. Once these have been determined, an action system (help-seeking behavior) is activated. EMs link beliefs and behavior within the context of people's experience. The explanations of breast cancer were collected in narrative form with EMs constructed for each of the three groups under study. Each narrative contained the following variables: (1) causes of breast cancer; (2) symptoms of breast cancer; (3) alternative treatment for breast cancer; (4) definitions of breast cancer; (5) expected treatment outcomes for breast cancer, and (6) attitudes toward breast cancer providers.

Decision modeling focused on discovering and testing individual's criteria for making treatment choices. Shared standards for decision making about health behavior will be used to construct a model that will predict the different treatment options that people can be expected to choose. People's knowledge structures and

conceptions of illnesses are inextricably related to their illness responses, and, consequently, to their decision making processes about treatment alternatives. The specific data that was systematically collected to construct decision models that include the following variables: (1) constraints of decisions about breast cancer treatment choice; (2) intuitive rules for making decisions; (3) rationale for making choices, and (4) sequence of choices of treatment.

Sub-Objective 1.1: Recruit and train the interviewers (research assistants) for the qualitative component of the study.

Senior or graduate students from three HBCUs near the target communities were utilized as research assistants. These institutions are Fort Valley State University, Savannah State University, and Albany State University. Students were selected from the disciplines of sociology, social work, allied health, and nursing. A faculty preceptor from each school assumed the responsibility for the on-site supervision of the student research assistants. Both students and preceptor were compensated for their efforts. This approach provided a number of advantages: cultural and geographic familiarity, interinstitutional collaboration, and cost effectiveness in terms of controlling per diem and travel expenses in connection with the ethnographic analysis.

During the first six months of the study, six (6) research assistants (2 for each of the 3 study areas) were recruited and trained in the methods of data collection and data management analysis. The Co-Investigator Hill on the MSM campus gave training session. The research assistants were trained in the following techniques: (1) field note taking; (2) systematic observation; (3) interviewing; (4) coding; (5) transcription; (6) use of data management programs (TALLY); (7) construction of individual and group profiles; and (8) computer assisted analytical programs, such as ANTHROPAC.

Sub-Objective 1.2: Recruit study participants.

Targeted or purposive sampling was used for selecting respondents (key informants) in each study site. Johnson has stated that the validity of the sample depends not so much upon the number of cases as upon the proper specification of the respondents.⁴ Nonprobability samples yield a representative picture of salient features of the target population; a small number of informants provide representative pictures of aspects of cultural knowledge distributed within the population.^{5, 26, 30} We attempted to minimize variation in knowledge for a single cluster of respondents in one site and while maximizing variation in knowledge among respondents at all sites.

Study Respondents were selected from relatively homogeneous site-specific populations and from comparably heterogeneous populations across sites. Although this type of study did not use random sampling, it is selectively sampling specialized knowledge of the key variables set forth in the study. Glaser and Strauss suggested that theoretical sampling in qualitative research (grounded theory) is important for minimizing and maximizing differences among groups in order to discover cultural categories and help identify emergent theoretical properties of cultural models.⁶

Twenty-five (25) subjects were sought from each target area using the following criteria: (1) low-SES, (2) African American descent, (3) diagnosis of breast cancer, (4) over 40 year old, and (5) lived in rural areas for past 15 years. Ethnographic research makes it possible to use smaller samples than quantitative data since the overall goal of qualitative research is depth, not breadth.^{30, 27} This number was sufficient to approximate a representative sampling for the study population in each site and guarantees intracultural variation within the sub samples. Once identified, subjects were recruited to participate in this study utilizing a pre-existing lay outreach system. Participants received a cash incentive for their contribution to the study. The purpose of the study and scope of participation was explained, and an informed consent was obtained.

Sub-Objective 1.3: Conduct the ethnographic assessment of belief systems.

Several ethnographic techniques were used to assess the cultural knowledge (beliefs) about breast cancer including interviewing, free listing, and participant observation. The research assistants carried out these techniques. A major criterion for selection of the research assistants was that they live in or near one of the target communities. They will involve themselves in local events, such as church functions and community events. They will take detailed notes of all observations and informal interviews. When possible, observations were made in households and other private gatherings.

An interview instrument, consisting of structured and semi-structured questions was administered. The instrument was designed to elicit descriptive information for determining the EMs and decision-making processes for breast health disorders. The interview instruments were pre-tested in a demographically similar community that is not proximate to the target areas. The respondents were asked about their beliefs about causes of breast disorders and related problems, why people have them, what they think about people who have them (attitudes), about symptoms (early recognition), what they did when a breast disorder event occurred (use of formal and informal systems), and how these disorders have affected their lives (impact on family, friends, community and work). These questions yielded in-depth information about rural residents' knowledge and experiences of breast disorders.

Another technique that was used is free listing. Respondents for each sub sample were asked to list the types of breast health disorders they know about and the treatments for each type of disorder. Free listing is a technique that allows researchers to explore the cultural limits of an area of knowledge, belief, or behavior.

Participant observation will be used, and is defined as those modalities that attend to interaction, context or situation and to narrative or case studies. An important aspect of this participation is interaction with residents in multiple contexts. Experience suggests that in multiple, ad hoc contexts, informants offer further insights on their cultural models and world-views that will directly inform the ethnographic modeling instruments that will emerge. Observational field notes will consist of two categories: (1) general observations, and (2) structured observations that are directly related to breast health and breast disorders. Field notes were recorded to assure confidentiality. No names will be used in the notes and the researchers will explain the anonymity of all participants. Researchers were given explicit instructions on the systematic collection and management of fieldnotes.

Having completed the initial ethnographic data gathering, these data were then used to construct hypothetical decision models for each sub sample. The model included all the health resources obtained through interviewing, the ordering of criteria, and the sequencing of choices. Decision rules were hypothesized about which conditions lead to the choice of a particular treatment alternative. They were tested for predictability on each sub sample of the research populations.

Belief systems that emerged from these qualitative techniques were measured for intracultural variations. Groups showing a high degree of information sharing about breast cancer were the consensus groups. Measuring intracultural concordance and variation for the purpose of constructing consensus models and their distribution for the three populations. The consensus modeling interview instrument used a frame technique to ascertain the structural elements of the breast health domain. Each respondent was asked to make pile sorts of cards that will have attributes written on them that represent dimensions of the breast disorder cultural domain generated from previous ethnographic research. They were also asked to make judgments about the similarities and characteristics of the named breast disorders by the first sub samples of respondents.

Sub-Objective 1.4: Analyze data.

Data management and analysis proceeded in four phases: (1) cross-coding the textual and structured data and entering it into the appropriate computer software program; (2) constructing a profile for each catchment area; (3) constructing demographic, cultural, and behavioral profiles for the sub samples; (4) constructing cultural consensus and decision models for the sub samples; and (5) comparing the sub samples for intercultural and intracultural concordance and variation.

Field notes were treated as texts, and transcribed and coded. Text coding was done on a weekly basis, using a precoded system worked out in the pilot study, and checked for reliability by requiring that at least two researchers independently code the text, and negotiate any differences by referring to the descriptive data collected during the interviews and participant observation. The codes were inserted into the text and matched with those in the semi-structured and structured interviews. Cross coding allowed for merging the different types of research techniques.

Interview data was analyzed by writing summaries for responses to each question for all sub samples. A context analysis for each response included identifying the primary and secondary themes, identifying the most frequent theme for each question, and describing the degree of variation or consensus in themes. The goal for inter-rater reliability was set at 90%.

Analysis included constructing a profile of the EMs for the three sub samples, aggregating their responses on the EM interview schedule. A summary of the demographic characteristics of respondents in each sub sample, e.g., age, educational level, income, employment, health insurance status, and history of breast disorders and related problems were made for each respondent and sub sample. These data were correlated with the resident's health seeking behavior in both the formal and informal systems. These profiles also included the analysis of their attitudes toward breast disorders.

Cultural consensus models were constructed for each sub sample by examining the agreement between respondents on what elements constitute the breast disorder domain. Analysis of the elements of this cultural domain involves algorithmic analysis to create a distance matrix. These relationships are analyzed using cluster analysis and multidimensional scaling, which transform the numbers into a visual representation of the relationships between respondents and among groups of respondents and of the relationships between variables and groups of variables. Cluster analysis was used to analyze the relationship between classifications of elements within a specific cultural domain. It allows for graphic representation of data groupings. Multidimensional scaling is used to represent spatially the elements of a domain and to estimate the number of underlying dimensions that organize respondents' classification of the data^{7, 8}. The aggregated responses for each group or sub sample were analyzed. Intercultural variation was examined by comparing the aggregated responses. Seventy-five women with a current or past diagnosis of breast cancer were targeted for the ethnographic survey. The rationale for interviewing women with a history of breast cancer was to make a pre and post diagnosis comparison of beliefs, knowledge and practices, then work backwards to use these findings for the development of our intervention study.

Belief systems and their variations of the three populations were qualitatively analyzed by using a set of data collection and analysis techniques grounded in symbolic and cognitive anthropology that assumes that people's behavior is guided by their interpretations of, and beliefs about breast cancer.

Procedures: The methods used in our study were in-home, face-to-face interviewing using an interview schedule; free listing to delineate cultural domains and pile sorting to delineate shared cultural categories for breast cancer. These techniques were chosen because they allow for collection of information on beliefs in a reasonable amount of time. These techniques also allowed us to understand how breast cancer beliefs are

organized in the mind of respondents and to provide a baseline for discovering variation in cultural knowledge in the three research sites.

Research tools included two instruments constructed specifically for this study: an interview schedule consisting of structured and unstructured questions and a personal information questionnaire, which elicited demographic information. Both instruments were pilot-tested for educational appropriateness and content validity, by written administration to fifteen individuals and in a focus group setting to 35, with breast cancer survivors demographically similar to but outside of the study areas.

Data collected was analyzed via focused coding methods that utilize the constant comparison approach to develop relevant themes (28,29). The interview schedule questions were designed to elicit descriptive information for determining the Explanatory Models (EMs) and decision-making processes for breast health disorders. Collected in narrative form, Explanatory Models (EMs) link beliefs and behavior within the context of people's experience the words of the respondent. They provide a person having breast cancer with a causal explanation for the disease. During the in-home face-to-face interview, the respondents were asked about their pre and post diagnosis beliefs about breast cancer and related problems. Each interview was audio taped, transcribed and compared to the written narrative to verify that the participants' perspective was accurately captured. Each narrative contained the following variables: Causes of breast cancer; symptoms of breast cancer; alternative treatment; definitions of breast cancer; expected outcomes, and; attitudes toward breast cancer providers. Shared standards for decision making about health behavior were used to construct a model that would predict the different treatment options that people can be expected to choose. The first question on the interview schedule asked for a narrative account of the women's experience with breast cancer. From these data an explanatory model was constructed for each woman in the sample. They were subsequently aggregated for each research site. Decision modeling focused on discovering and testing individual's criteria for making treatment choices. Shared standards for decision making about health behavior were used to construct a model that predicted the different treatment options that people can be expected to choose. People's knowledge structures and conceptions of illnesses are inextricably related to their illness responses, and consequently, to their decision making processes about treatment alternatives. The specific data that was systematically collected to construct decision models include the following variables: constraints of decisions about breast cancer treatment choice, intuitive rules for making decisions, rationale for making choices, and sequence of choices of treatment.

Because cancer databases for the state of Georgia were incomplete for several of the counties our study targeted and the challenges encountered in gaining access to existing files on demographically similar counties, we use a grassroots effort to develop our own registry of African American breast cancer survivors. Utilizing existing relationships between Morehouse, local medical facilities, health departments, professional associations, and community-based agencies/organizations, representatives were contacted for assistance with publicizing our study and recruiting participants. Additionally, flyers were disseminated at medical facilities, churches, community centers, senior centers, grocery stores and other common gathering places for African American females. Cancer support groups, home health agencies, and medical facilities, particularly cancer treatment centers, were the most helpful in this regard. While this route proved to be more laborious than accessing existing registries, the effort was worth the time and energy because it provided more opportunities for direct community involvement and proved to be an excellent learning experience for staff and students.

Once our registry was developed, these workers experienced little resistance to participating in the ethnographic survey. The major problem in connecting potential participants with the study was the distance between the interviewer and the study participant. This is a geographical barrier common to research in rural areas (30).

Participant Recruitment: Targeted or purposive sampling was used for selecting participants in each study site. They were selected from a relatively homogenous site-specific population and from comparable heterogeneous populations across sixties. The targeted sample number was 75 (25 from each site). The

following criteria were used for selecting respondents: Low SES (\$17,000 yearly Household income or less); 40 years old and older, and lived in rural areas for past 15 years. Once identified, our Lay Health Workers recruited participants into this study. The Lay Health Workers administered the personal information questionnaire and referred each respondent to the research assistants who obtained the informed consent and conducted the interview. Upon completion of the interview, participants received a cash incentive.

Data Gathering: The methods for collection of data were formal interviewing using an interview schedule and free list and pile sort techniques (see appendix). Questions were designed to elicit descriptive information for determining the explanatory models, decision models, and cultural domain of the targeted population. For example, respondents were asked about their beliefs about the cause and symptoms of breast disorders, why people have the, what they think about people who have the disease (attitudes), what kind of support they have for managing the disease (use formal and informal systems), the relationship between religion and cancer, and where they learned about the disease and its management. Each respondent was also asked to list the causes, symptoms, and treatments for breast cancer. This technique allowed for an analysis of the cultural limits of breast cancer; its cultural domain was delineated. Pile sorting is a technique that allows for an analysis of similarities of cultural categories used by the samples. Respondents were asked to make judgments about the similarities and characteristics of the causes, symptoms, and treatments for breast cancer.

In addition, a personal and demographic information questionnaire (see appendix) was administered before the major research instrument. The interview instrument included an extensive narrative chronicling the experiences of each respondent with breast cancer. Research assistants trained in qualitative interview methods conducted these interviews. In order to ensure that the data collected was an accurate representation of the subjects' views versus the filtered perspectives of the interviewers, each interview was audio taped. These audiotapes were transcribed and used to verify and enhance information collected by the research assistants.

Train new Interviewers: Because of the delay created by having to develop a registry in some of the counties where subjects were recruited, some of the research assistants completed their course of study at the universities and moved out of the study areas. This created the need to recruit and train new interviewers who subsequently completed the interviewing process.

Completion of Data Collection: Data collection was completed in month 17 of the study.

Accomplishments: These data collection methods yielded 64 completed questionnaires that averaged 15 written pages per subject and 10 to 20 pages of transcriptions from the audiotapes.

Problems Encountered: The problems encountered in Year One were also experienced in year 2. Because the state database on breast cancer case was not available to this study in some of the counties where the recruitment took place, researchers had to develop a registry of breast cancer cases. This caused a delay in identifying, recruiting and interviewing study subjects. This was particularly true in the Fort Valley area.

Data Coding and Management: This process proceeded in four phases: 1) cross-coding the textual and structured data and entering it into the appropriate computer software program; 2) constructing a profile for each research site; 3) constructing demographic, cultural, and behavioral profiles for the sub samples; 4) constructing cultural consensus and decision models for the sub samples; and 5) comparing the sub samples for intercultural and intra cultural concordance and variation.

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in the semi-structured and structure interviews. Cross coding allow for merging the different types of research techniques.

Data Analysis: Interview data was analyzed by writing summaries for responses to each question for all sub samples. A context analysis for each response included identifying the primary and secondary themes, identifying the most frequent theme for each question, and describing the degree of variation or consensus themes. The goal I for inter-rater reliability was set at 90%. Analysis included constructing a profile of the EMS for the three sub samples, aggregating their responses on the EM interview schedule. A summary of the demographic characteristic of respondents in each sub sample, e.g., age, educational level, income, employment, health insurance status, and history of breast disorders and related problems was made for each respondent and sub sample. These dates were correlated with the subjects' health seeking behavior in both the forma and informal systems.

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Findings: The findings from this ethnographic phase of the study were both confirming of previous research and providing of new insights into the belief structure of rural, southern African American women. A comprehensive analysis report is available and will be submitted with the final report of this study. The following is a summary of the salient as these relate to the three assumptions (hypotheses) that directed the ethnographic survey:

- The belief system of African American women with breast cancer at the three sites in rural Georgia combines traditional and biomedical beliefs, confirming previous studies on breast cancer and belief systems in general among southern African Americans.
- Women at all three sites used the same terminology as medical professional to describe breast cancer, but they do not necessarily share the same meaning of these terms. This finding is significant for understanding the communications processes between health and medical professionals may be hampered by the use of the same terms but not sharing the same meaning, i.e., mammography as a treatment whether than a screening tool.

- Home remedies were acknowledged in fifty-seven percent of the respondents at the Savannah site as a form of treatment. Home remedies included garlic, vinegar, tofu, vitamins, nuts, fruits, and even marijuana.
- Faith was the top choice for treatment at all sites. The responses clearly opted for a medical treatment with faith as an essential part of that treatment.
(See Figure, 3: Explanatory Model for Breast Cancer Treatment)
- The most frequent terminology used to describe symptoms of breast cancer by women in all three sites reflects a biomedical perspective (see Figure 4). However, there were significant differences between sites in motivation to get breasts checked by a doctor. Having pain was the more prevailing motivation for the Fort Valley and Savannah sites. More respondents at the Albany site found lumps without pain than the other sites and this was the most prevailing motivation to visit the doctor.
- Regarding respondents' perception of causes for breast cancer, heredity, lifestyle and diet were top responses for all three sites, except the Savannah site differed in their causal beliefs about tobacco, violence, and faith. Violence (defined as being hit or sucking by men, injuring themselves by falls) was cited only four percent of the time by the other sites, but was cited twenty-six percent of the time by the Savannah respondents (see Figure 5).
- Regarding biomedical breast cancer knowledge, when asked how they described breast cancer before their diagnosis, silence or not being able to describe it is the most common response across the sites (see Figure 6).
- Most women in the survey reported visiting a doctor immediately upon experiencing symptoms of breast cancer. However, twenty-six percent waited over a month to visit a doctor and seven percent over a year. Reasons for delay included waiting for the lump to go away, not wanting to know if it was cancer, having a prior history of benign cyst, and experiencing difficulty scheduling an appointment with a doctor. These delays were seen primarily in the Fort Valley and Savannah sites (see Figure 7).
- Regarding social support, seventy-five percent of all respondents consulted a family member (child, parent, sibling, husband) about symptoms and diagnosis. Of this group, fifty percent talked first to their husbands.
- Thirteen questions were asked in an agree - disagree format about religious beliefs and church support (Table 3). In addition to these, questions about how faith helps women to understand their diagnosis of breast cancer were also asked in the ethnographic interview. For all sites, five beliefs indicated strong across site agreements:
 1. God works through the doctors and nurses to cure cancer;
 2. You would trust more in God to cure your cancer than medical treatment;
 3. It would be your responsibility to pray everyday that God would cure you;
 4. The strength of your own faith in God would determine if your cancer was cured; and,
 5. You would want your church members to come to the hospital to pray with you.

Differing from the other sites, the Savannah site, regarding not asking people to pray for them in church (public forum), One hundred percent indicated that they would not ask people in church to pray for them. See figure 8 Agreement on religious beliefs.

In order to discover the samples sources of information about breast cancer, of the information presented, the TV, books, pamphlets, newspapers, magazines and doctors were the most often chosen. Of these the doctor was the most trusted. See Figure 8 and 10.

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- ❑ Home remedies were acknowledged in fifty-seven percent of the respondents at the Savannah site, as a form of treatment. Home remedies included garlic, vinegar, tofu, vitamins, nuts fruits, and even marijuana.
- ❑ Faith was the top choice for treatment at all sites. The responses clearly opted for a medical treatment with faith as an essential part of that treatment. (See Figure, 3: Explanatory Model for Breast Cancer Treatment).

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In order to discover the samples sources of information about breast cancer, of the information presented, the TV, books, pamphlets, newspapers, magazines and doctors were the most often chosen. Of these the doctor was the most trusted. See Figure 8 and 10.

A total of 64 respondents were interviewed. Table 1 summarizes the demographic profiles for each site.

Ethnographic findings only partially supported the assumptions of our ethnographic survey. For the first assumption, the findings indicate that women who live in more isolated sites sought preventive care as often or more often than those women at the least isolated site. Women who have more access to complex urban systems were no more likely to seek preventive medical care than the women in the other two study sites. The ethnographic findings, however, upheld the third assumption that cultural beliefs about preventive care are strong persuasive agents for seeking medical care services for breast cancer. While affording medical services and transportation were problematic for some respondents, particularly those who did not drive, these

factors were not as persuasive as cultural beliefs. Coding of the ethnographic interview and narrative occurred in stages, each stage building in complexity from identifying and tagging single codes, to exploring relationships among coded which general cultural themes and patterns. Frequently assigned codes followed three themes: codes about prevention and treatment knowledge and behavior and social support.

Pre-Diagnosis Beliefs: Ninety-five percent of participants did not think about the disease; 65 percent did not discuss it with anyone; 50 percent believed they had no symptoms. Indicating that few symptoms appeared in this group or symptoms were not recognized, both significant issues to explore in future research. Some did not seek help immediately after finding a lump. Seventy-five percent had regular doctors and regular visits. While most doctors' offices displaced information about breast cancer and other diseases, participants reported receiving little or no instructions on the breast self exam or strong emphasis to get mammograms from their doctors.

Post-Diagnosis Beliefs: At the point of diagnosis and subsequent medical treatment, the women's beliefs changed to: use of medical terms learned from their experiences with breast cancer for their symptoms, causes and treatments, however, the distinction between diagnostic procedures and treatment was not clearly understood. Nonetheless, this medicalization process results in an increased use of preventive care and an increased level of communication about the disease. Terms and concepts learned in their diagnostic and treatment experiences were framed within a religious context. More than 90 percent believe that faith helped them survive the disease. Belief that God works through doctors increased trust in the medical system and demonstrated a truly integrative belief system between religion and medicine. This finding is consistent with previous studies regarding the role of religion in health behavior. Jahn (31) explains that from an Afro centric perspective, it is not possible to separate Theology from medicine or vice versa without violating the entire worldview of the group. All women believed that God works through the medical providers; medical providers who demonstrated a spiritual component to healing were most trusted and more likely to receive compliance from them as patients. These findings verify that the medical setting is a critical context for increasing health promotional messages and that breast-health messages personalized for African American women need to be transmitted to medical personnel.

Site Variations: (need to explain sites better regarding issues of isolation verses easy access. To date, there appears to be more similarities than significant variations between the sites. The variations in cultural knowledge and behaviors appear greater between the Savannah sites and the other two, Albany and Macon. However, it must be noted that some of this variation may result from the smaller sample size in the Savannah sites. For example, in response to the question "Who did you first talked to about your breast cancer?": Albany Health District: sisters, daughters, doctors, husbands, female friends; Savannah: older female relatives, doctors, husbands; Macon: husbands, doctors, other family. Friends, ministers, and co-workers were the least mentioned first-talk choices across sites. This finding is consistent with Dressler's studies of rural African Americans, which stressed the extended kin network more than friends as protective against depression (32). Findings from the Save-our-Sisters project in rural North Carolina, show that support from female peers has been a significant predictor of accepting recommendations, following through with scheduling, and keeping appointments with

mammography, even after controlling for physical health status, age, education type of insurance and source of care (33). While all of the study participants wanted others to pray in church for their recovery, the Savannah site participants were more likely to prefer private prayer in their homes. Additionally, as seen in Figures 1 and 2, there were notable differences in the most trusted sources for receiving health education information. These between site variations suggest possible differences in intervention strategies.

Our findings also suggest that the quality of advice received either promotes visiting a doctor or trying other treatments first, including the length of time she delays visiting a physician. Social influences through informal networks are pertinent for breast cancer screening. In summary, tentative decision models for help seeking behavior were constructed from the ethnographic data (Figure 3). Criteria were selected based on the findings of the explanatory modeling and the cultural domains for symptoms, causes and treatment.

The decision tree generated from the overall sample suggests the criteria affecting the decision-making process of African American women to go to the doctor and reduce diagnosis delay. This model is viewed as a hypothesis only for seeking medical care. This decision tree for going to a doctor has not been yet tested on a second and third sample and is, therefore, not a predictive model of the help-seeking process of African American women regarding breast cancer. It does, however, illustrate the preliminary criteria involved in going to a doctor for this sample.

Focus Group Sessions: Many participants in this phase suggested that researchers for the study interview women without histories of breast cancer before developing the intervention. Due to time constraints we were not able to conduct individual interviews, but did benefit from data from focus groups conducted for a Morehouse health communications project targeting African American women regarding video messages. These results enhance our message development process.

Table 1: Demographic characteristics of counties in three study sites

Counties	Total Population	% Pop. Black	Average Income	% Pop. Income >200% of Poverty Lev.	No. General Doctors	No. Hospital Beds	% Adults with high school dipl only
Baker	3,875	51	18,458	46.5	1	0	53.5
Calhoun	6,606	59	20,698	36.7	3	40	52.2
Dougherty	89,639	50	27,933	54.5	85	334	67.5
Houston	62,924	22	29,348	71.0	59	225	79.5
Liberty	17,569	50	21,643	40.0	5	50	82.0
Monroe	10,991	32	27,708	62.0	5	40	66.0
Peach	15,990	48	25,793	55.0	12	76	68.0
Twiggs	8,222	46	24,158	48.0	9	0	48.0
Worth	14,770	31	23,757	51.0	10	50	53.0

Source: Georgia County Snapshots, Georgia Department of Community Affairs, 1996

Table 2. Demographic Characteristics of Study Sample

Site Respondents	Mean age (range)	Mean Income	Yrs resident	PD	C	MC	PI	M/M	FFS	Oth	num
Fort Valley		\$15,600	33	88	4	8	64	16	8	8	25
Albany		\$16,667	27	84	12	-	52	16	12		25
Savannah		\$15,385	34	57	14	-	43	29	7		14
Total	55 (xx-xx)	15,968	31	77%	10%	8%	53%	20%	9%	8%	64

Years elapsed since diagnosis of breast cancer: Fort Valley=8 yrs; Albany=3 yrs; Savannah=7 yrs

Legend: PI=Private Insurance i.e. PPO, HMO, Indemnify
M/M=Medicaid/Medicare
FFS=Fee for Services
Other=Uninsured/Non Respondent
MC=Military Coverage/Insurance
PD=Private Doctor
C=Clinic

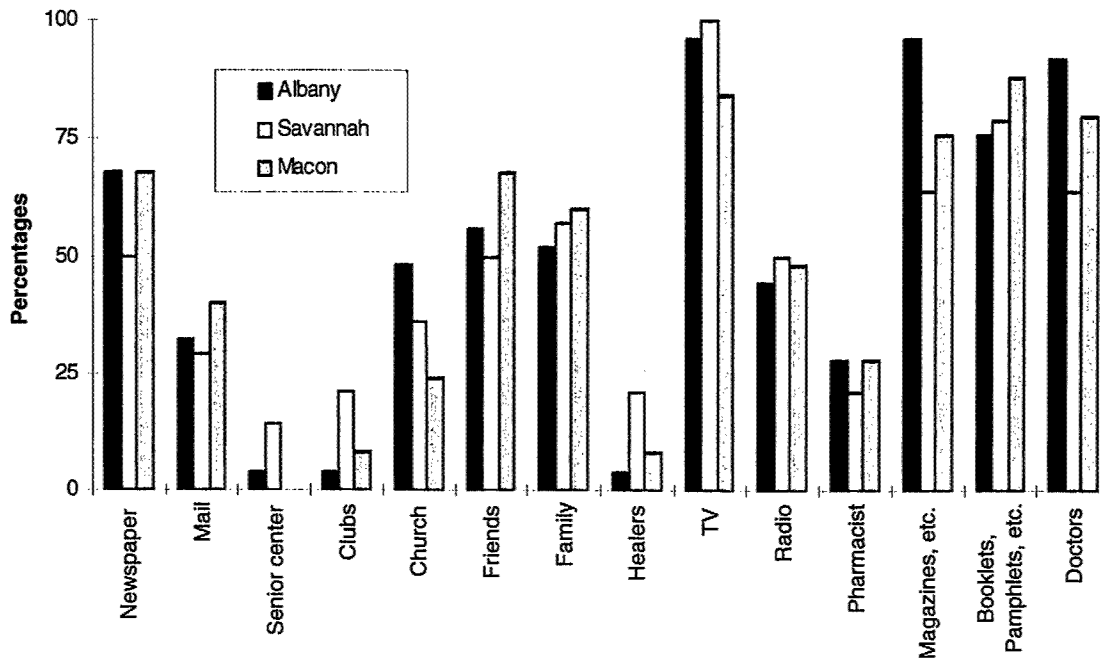


Figure 1 : Sources of Information About Breast Cancer

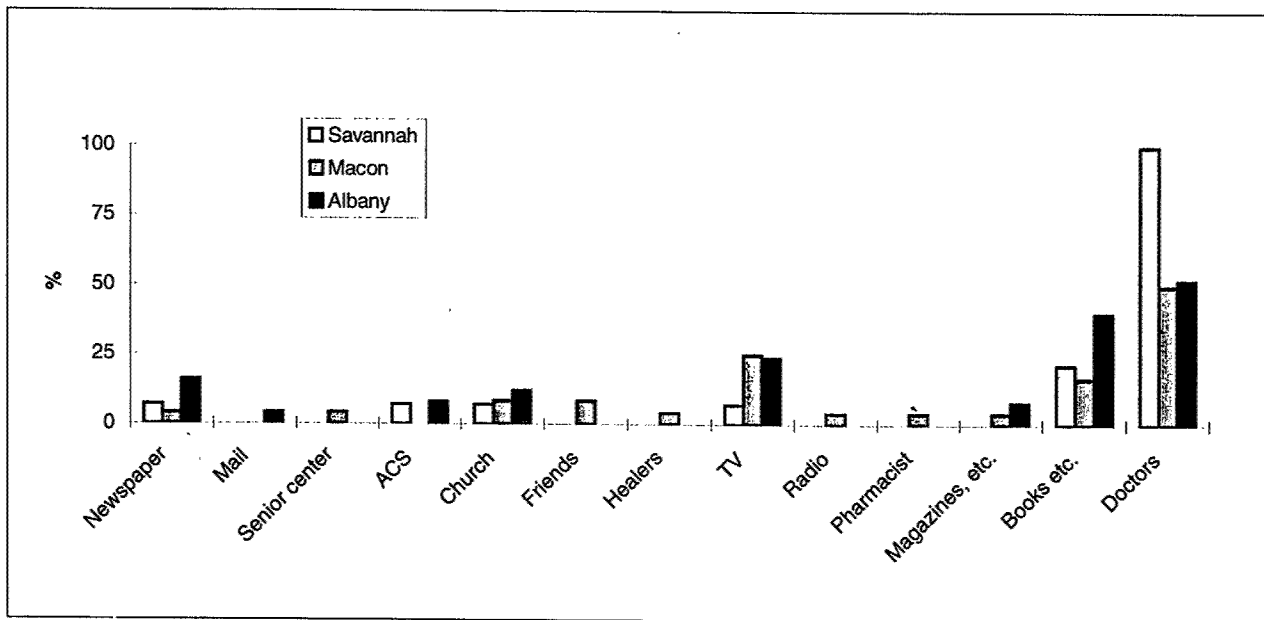
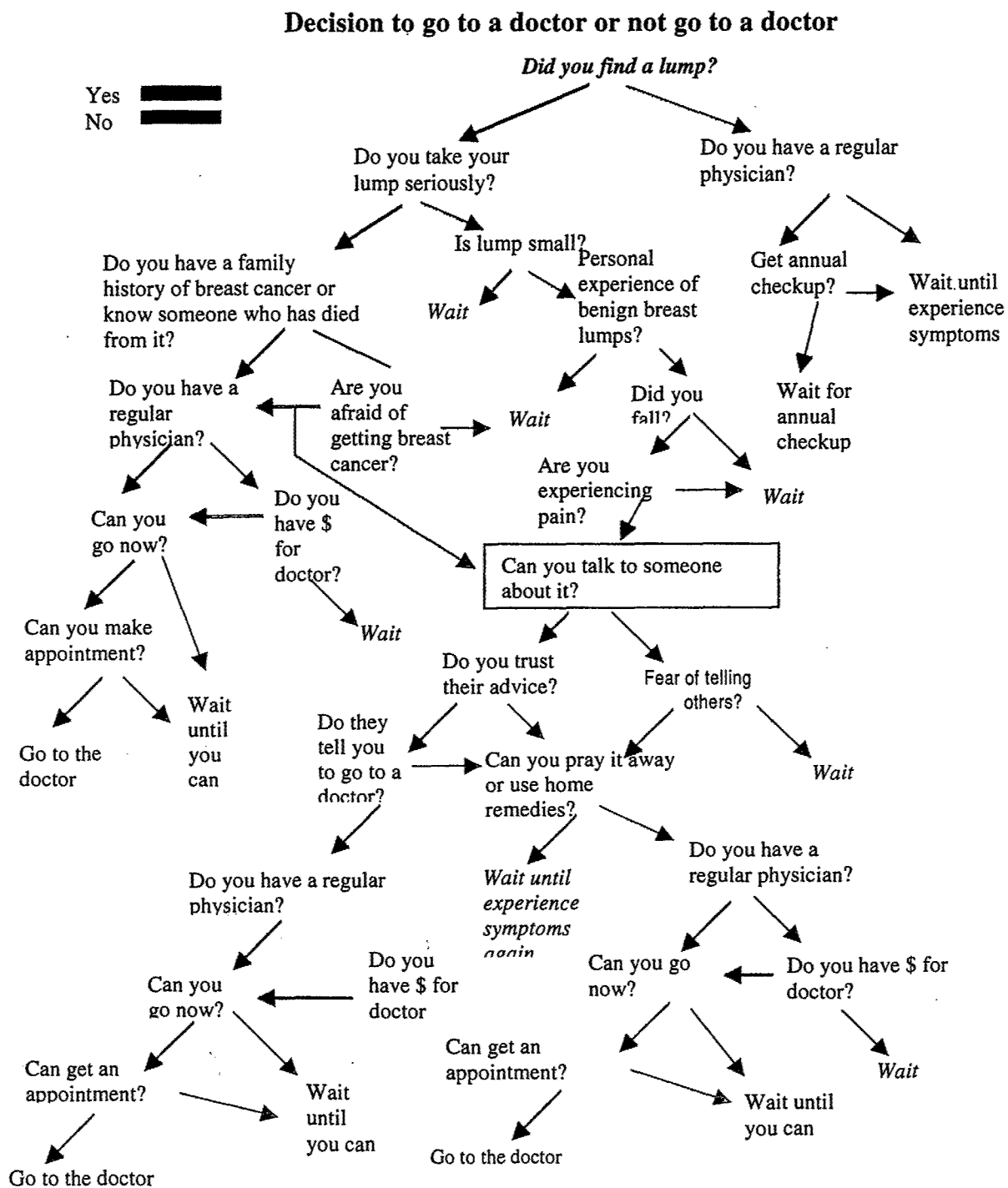
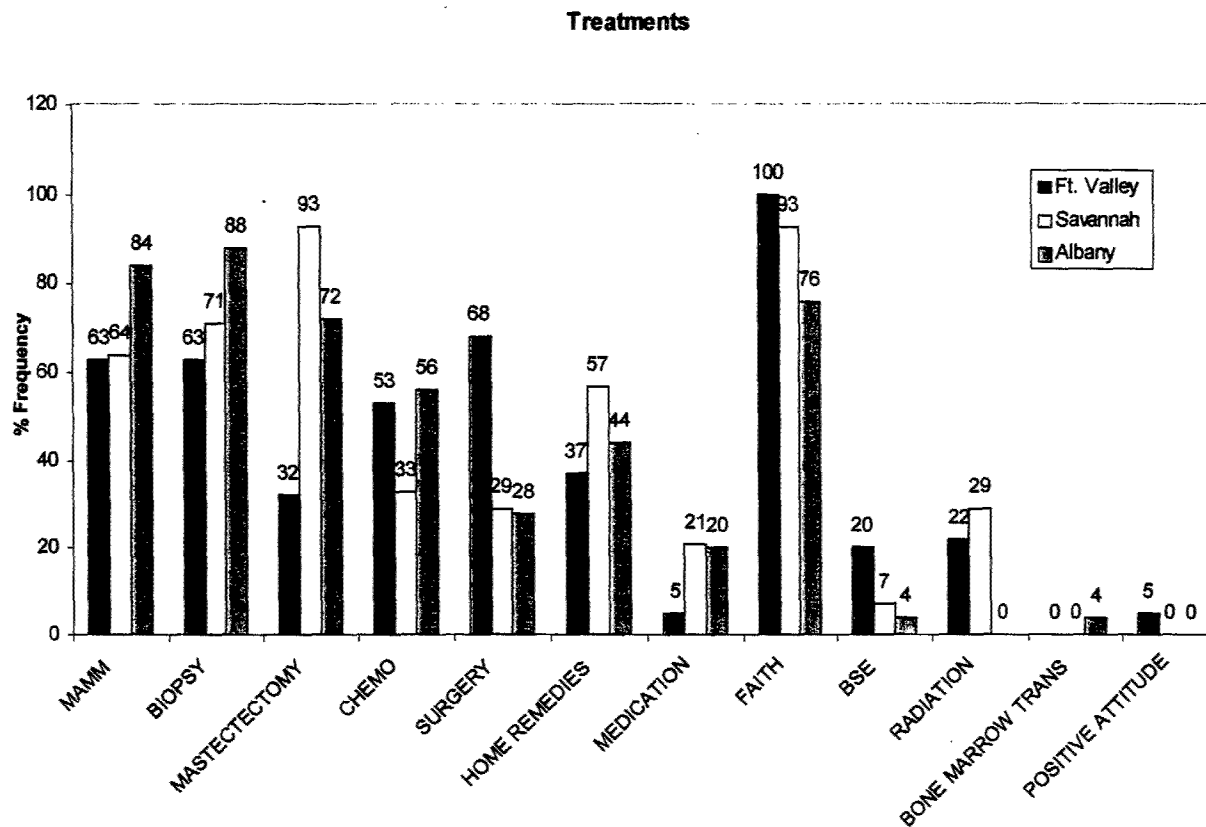


Figure 2 : Most Trusted Sources of Information

Figure 3 Decision Model: The Decision to Go To A Doctor



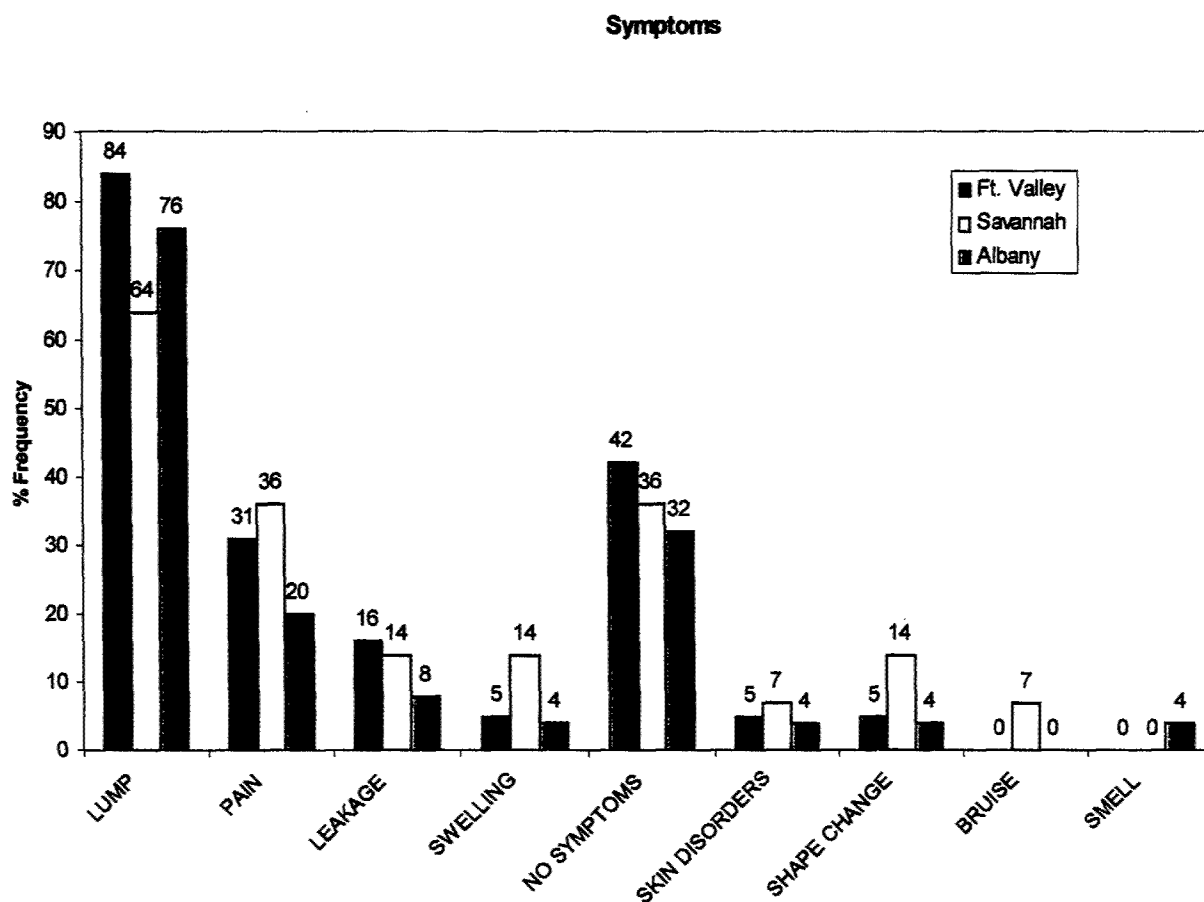
Treatment



Mamm = (mamogram), Faith = (faith, prayer, faith healing, scripture), Biopsy, BSE = (breast self exam), Mastectomy = (mastectomy, removal), Radiation = (radiation), Chemo = (chemotherapy), Bone Marrow Transplant, Surgery = (lumpectomy, removal), Positive attitude, Medication = (tamoxifen), Home remedies = (garlic, vinegar, honey, shark cartilage, nuts, pine bark, tofu, soy, roots, onion, tomato, wheat flour, grape juice, grapes, teas, tonics, cantaloupe, fruits, vegetables, aloe, oils, laetril, herbs, marijuana, vitamins)

Figure 3: Explanatory Model for Breast Cancer Treatment

Explanatory Models for Breast Cancer Symptoms



Lump = (lump, knot, mass, tumor, bump, lump under arm), Shape change = (hardening, heaviness, thickening), Pain = (pain, soreness), Smell, Leakage = (leakage, blood, spotting, discharge), Bruise, Swelling = (swelling, gland, size change), No symptoms = (no symptoms, no pain symptoms), Skin disorders = (rash, skin color, welts, itching, black spots)

Figure 4:

Causes

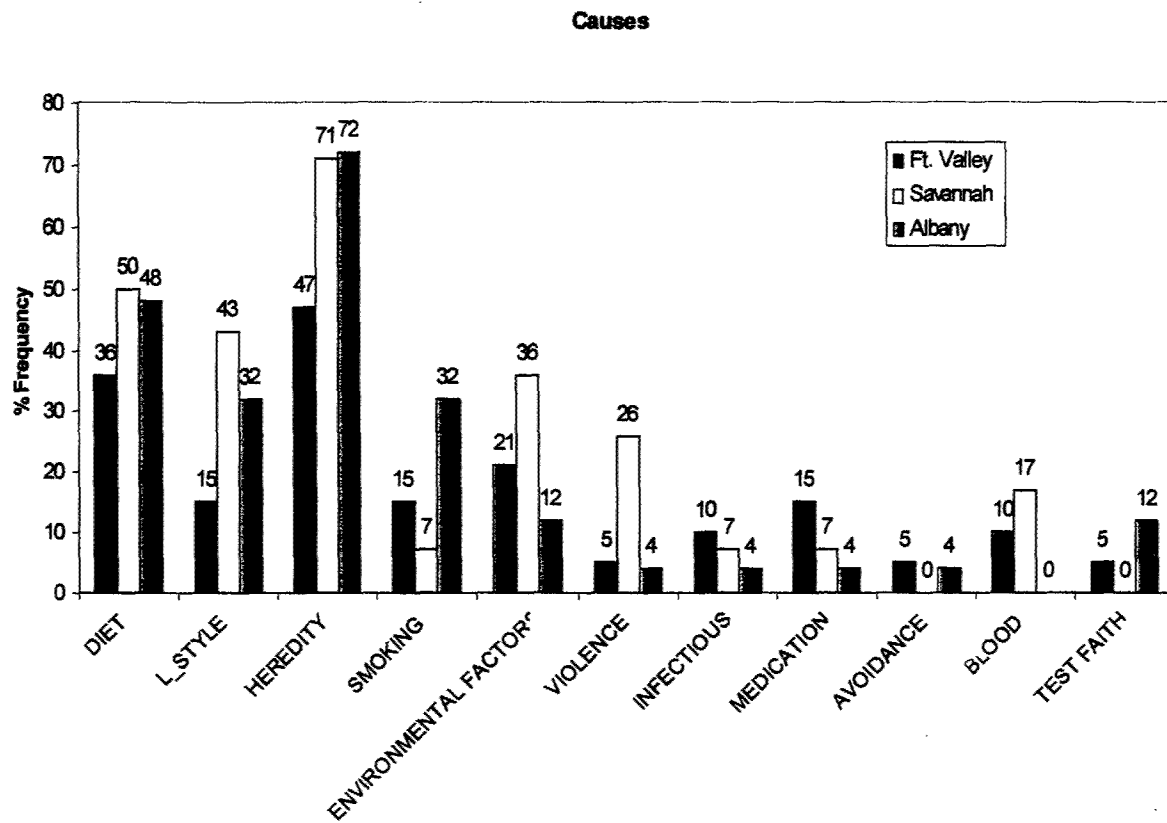


Figure 5: Explanatory Model for Causes of Breast Cancer

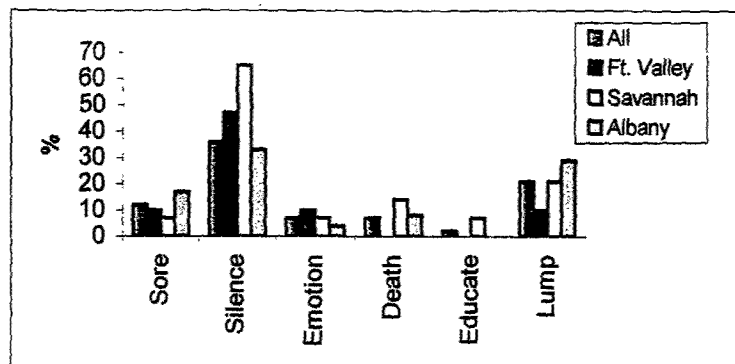


Figure 6: Breast Cancer Before Diagnosis

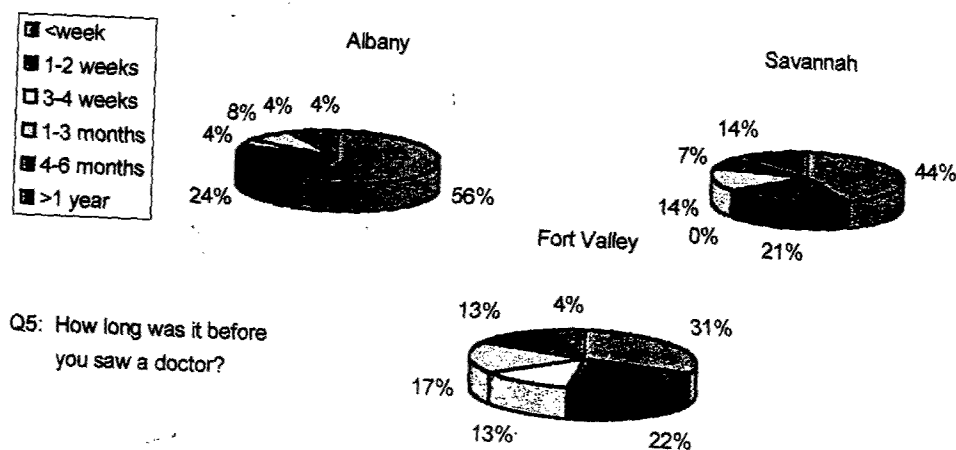


Figure 7: Delay in Seeing a Doctor by Site

Table 3: Agreement of Religious Beliefs

		Agree
1	God would work through the doctors and nurse to cure cancer.	91%
2	You would trust more in God to cure your cancer than medical treatment.	64%
3	You would refuse medical treatment and trust only in God to cure cancer.	2%
4	Only a religious miracle treatment could cure your cancer, not medical treatment.	16%
5	Your cancer would be because you had sinned against God.	2%
6	It would be your responsibility to pray every day that God would cure your cancer.	78%
7	The strength of your own faith in God would determine if your cancer was cured.	71%
8	Your prayer alone would do nothing to cure your cancer.	24%
9	You would want your church members to come to the hospital to pray with you.	72%
10	Your church members praying in church would help to cure your cancer.	64%
11	There would be a special ceremony for you in your church to cure your cancer.	17%
12	You would not tell anyone in your church about your cancer.	9%
13	You would not ask people in church to pray for you.	29%

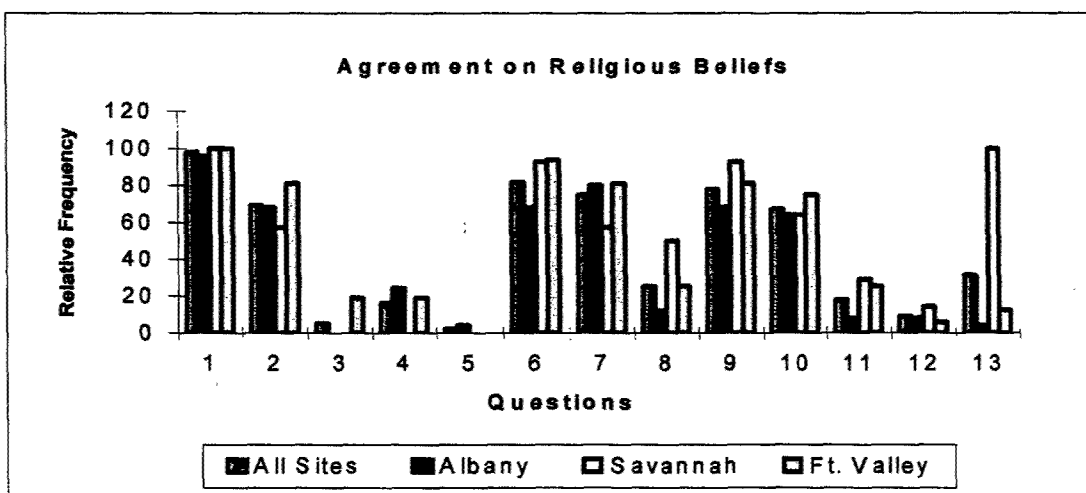


Figure 8: Religious Beliefs by Site

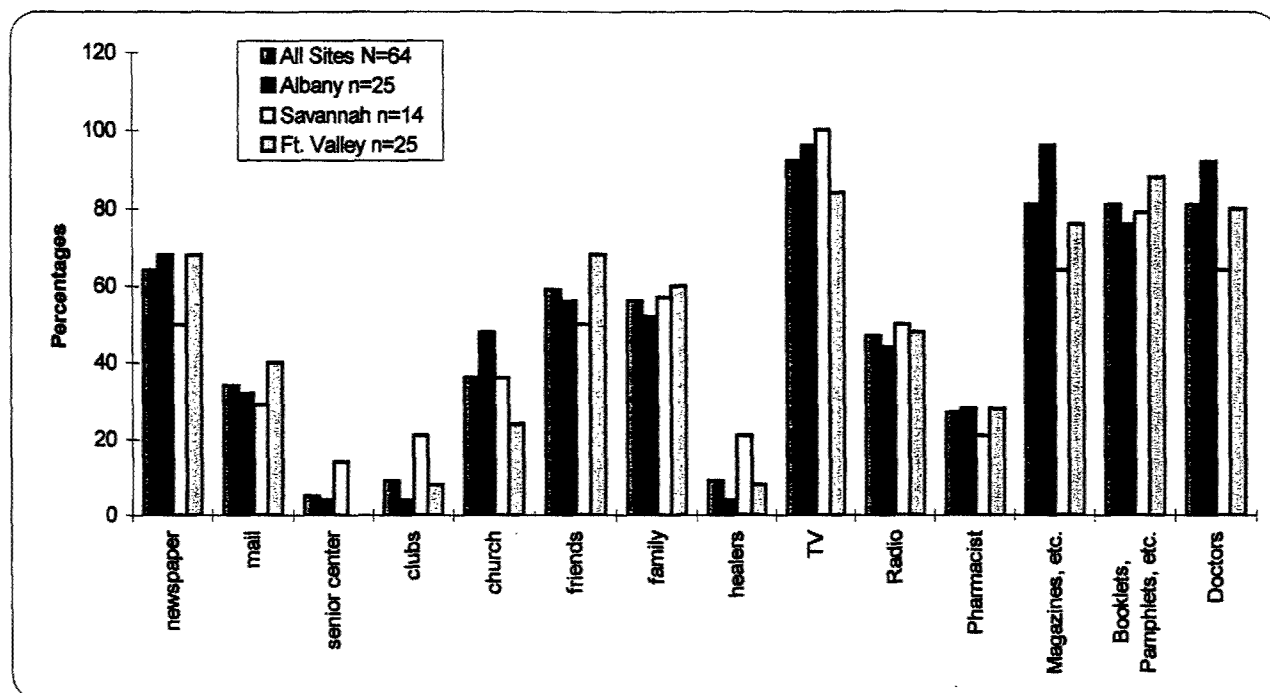


Figure 9: Sources of Information

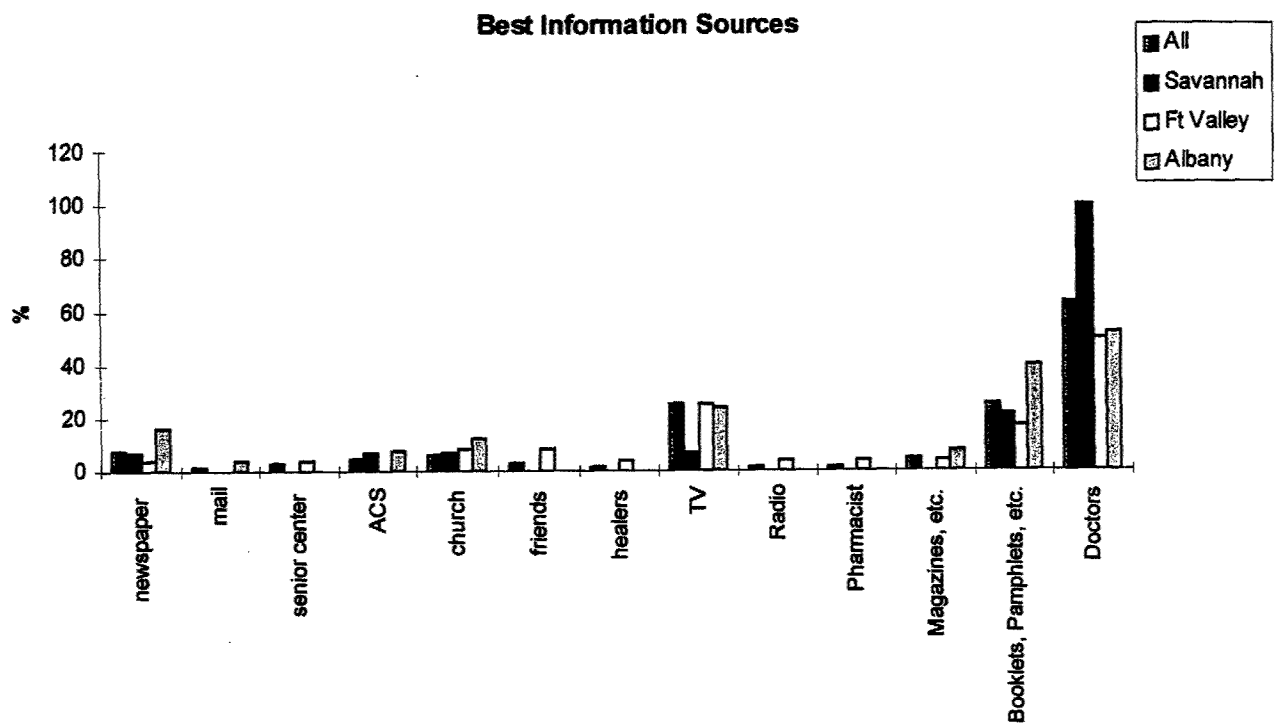


Figure 10: The Most Trusted Sources of Information by Site

MESSAGE DEVELOPMENT

Phase Two: Formulation of the interpersonal Message and Diffusion Strategies.

Several emerging communication models, e.g., Witte's (34) Persuasive Health Message (PHM) Framework, have expanded the purely cognitive/behavioral approach to health promotion by integrating cultural, environmental, knowledge, attitude, and belief variables into message development. Population profiles for each of our study sites were developed from ethnographic, demographic, and environmental data collected in Phase One. Analysis of the data from our ethnographic survey provided the basis for developing the diffusion strategy. A combination of these components (population profile, how cultural, environmental, knowledge, attitude and belief variables were integrated into the message) yields a message that is uniquely personalized to our study population. What is the message? The approach.

An understanding and respect of a target group's beliefs, values, attitudes, worldviews, social organization, and socialization are important factors of cultural sensitivity in health messages. These factors personalize the message through enhance significance, credence, and comprehension, and increase the likelihood of that the target audience will understand and accept the recommendations. A number of factors frustrate the formulation of effective, behavior-changing health communication. Health information and recommendations are traditionally based upon epidemiological findings that do not often include a broad, in-depth assessment of culturally driven behaviors that are especially prevalent in multiethnic and multi cultural societies. Further, health promotion campaigns usually exhort people to change deeply rooted beliefs and behaviors that have been continually reinforced over a lifetime, and perhaps throughout preceding generations. Social scientists and health communications researchers have held that if health promotion campaigns are to influence the audience as intended, they must be culturally, demographically, and geographically appropriate.

Development of the educational message on breast cancer and its detection and prevention has already begun. Themes (what were these themes) emerging from the findings of the ethnographic Survey are being used to construct a model using the Witte's Persuasive Health Message (PHM) framework as a guide because it takes cognitive, affective, and sociocultural variables into consideration (show how the message was developed using this framework. Tie in the cognitive, affective, and socio-cultural variables.

The PHM framework will provide the blueprint for the content of the message. Specific information components include basic information on breast health and breast disease, risk factors for low-income and minority women, the diet/nutrition/stress information, the importance of early detection, screening guidelines and resources, and referral information.

While thematic content forms the bedrock of the message, and influences whether or how the message is received and processed, diffusion strategies deal with how information is communicated through certain channels over time among members of a social system.

The Community-based Diffusion Model developed in collaboration with the National Heart, Lung and Blood Institute will be utilized. This approach bears a number of similarities with the Braithwaite-Lyhcott Model for community organization for health promotion. The Community-

based Diffusion Model recommends an understanding of the role, pattern of use, and the impact of the local, mainstream health care system such as private physicians, neighborhood clinics, hospital emergency rooms, and other health care resources. It is anticipated that in some communities, health care may be obtained through obscure venues such as herbalists and folk healers. For members of a target community who continue to hold traditional health beliefs, it will be more effective to fit new health information into the old frame of reference rather than to dismiss traditional beliefs as ineffective or superstitious.

ACCOMPLISHMENTS: a system of diffusion has to be identified and contracted to diffuse the education message. Home economist aides with the Fort Valley Cooperative Extension Service will be trained to deliver the breast cancer educational message. This community-based system has been in place for years and is a trusted resource of the targeted counties.

The content for the health messages was taken from publications of the National Cancer Institute and the American Cancer Society and adapted, as needed, to an eight-grade reading level. Topics covered include signs and symptoms, risk factors, prevention measures, importance of early detection, treatment options, and how to obtain referral information. Diffusion strategies deal with how information is communicated through certain channels over time among members of a social system. Our diffusion strategy utilizes elements from the Community-based Diffusion Model (35) and the Braithwaite-Lythcott Model(36) for community organization for health promotion. Both models recommend an understanding of the role, patterns of use, and the impact of the local, mainstream health care systems such as private physicians, neighborhood clinics, hospital emergency rooms, and other health care resources. For example, since one of our study sites included counties situated along Georgia's Sea Island coast, we anticipated that some respondents may practice folkways handed down from their west African ancestors and may obtain advice from complimentary health providers such as herbalists and folk healers. "For members of a target community who continue to hold traditional health beliefs, it will be more effective to fit new health information into the old frame of reference rather than to dismiss traditional beliefs as ineffective or superstitious" Ashante (37).

INTERVENTION: PHASE THREE

Objective 3: Develop the intervention delivery system.

- Sub-Objective 3.1: Develop curriculum and conduct training workshop for lay health workers.
- Sub-Objective 3.2 Develop primary/secondary support systems.
- Sub-Objective 3.3 Recruit study sample.
- Sub-Objective 3.4 Conduct Intervention.
- Sub-Objective 3.5 Track productivity of lay health workers.

Important to the diffusion strategy is who carries the message. The message carriers in Phase Three are lay health workers selected because of their position of trust and support giving within the social networks of the intervention population. Both the informal and formal model of lay health workers is used in this phase of our study. Our formal model utilizes Cooperative Extension Program Assistants (CEPA) who is paid employees of the Cooperative Extension Service. These individuals have been trained to work directly with County Extension personnel in assigned programs of nutrition, agriculture, family services, youth development, and health promotion. A CEPA provides clients with direct assistance through home visits and/or other gatherings. Most have a high school education supplemented by in-service education in the fields of home economics, agriculture, or food service and nutrition. Our informal Lay Health Workers are volunteers in a community center. Utilizing this approach has several advantages: it piggybacks on a well-established community-based agency with ongoing, structured relationships with the targeted communities and provides the opportunity to evaluate the effectiveness of both models. Most importantly, it leaves the community with members who have more skills and knowledge about implementing health promotion campaigns.

Training of lay health workers: This included providing a clear understanding of why the study was being done, preparation of the participant prospect list, selecting study participants, confidentially, data collection, recording keeping, making referrals, following research protocols, and delivery of the intervention. The training curriculum included basic information about breast cancer such as statistics, risk factors for low-income and African American women, the diet/nutrition/stress information, the importance of early detection, screening guidelines and procedures, information resources, and a demonstration on how to properly do self breast examinations. Nine talking points are highlighted as a guide for the information that each Lay Health Worker must cover during the intervention. However, the Lay Health Worker has the liberty to adapt her presentation of the information to the communication type most comfortable to the participant. Both the message and delivery were pilot-tested among demographically similar women living in rural communities not targeted by the proposed research. Role-plays were used to provide opportunities for hands-on learning and evaluation of the trainee's ability to implement the intervention. Each trainee received a study package, which included written step-by-step instructions on how to conduct the intervention, and demonstration on the breast self-examination. Their package also included breast model for demonstration. Technical support and remedial training occurs on an as-needed basis throughout the implementation. Six Lay Health Workers (four CEPAs and two community volunteers) have been trained to recruit participants and delivery the intervention. The recruitment and training of these educators reflected both the existing roles they have in their respective communities and those proposed by the programs to which they are recruited. The training was conducted by the study's principal investigator (a health educator and clinician), a co-investigator (a health communications specialist) and a registered nurse.

Talking Points: While each lay worker was encouraged to use her own type of communication to deliver the message, talking points were developed in order that each lay worker would be remained to cover all of the material in the program and to ensure that each interview include all of the information included in the intervention. Those talking points were:

1. Importance of preventive behavior (reinforcement); personal empowerment
2. Good health is a spiritual gift.
3. Evaluation of risk; nutrition; obesity; family history; smoking
4. BSE, clinical exam, mammographic procedures
5. Fear of diagnosis, or of curative/surgical intervention
6. Fear of discomfort with BSE (relating to auto-stimulation) or mammography
7. Issues relative to spouse and/or family support
8. Issues relative to expense; sources of funding, SSI information
9. How to talk to, listen, and understand the doctor. Taking a friend/spouse with them to doctor visits if needed.

Study Participant Description and Selection. Intervention sites are three counties, which meet, previously mentioned the site selection criteria. The study sample consisted of two groups, A and B. Criteria for selection as a member of the study includes the following: African American female aged 40-65; current resident and native of target community; no history of breast cancer; no history of breast surgery; no history of mammogram in the 12 months preceding the study (women 50 and older) and 24 months (women less than 50). Group A received the intervention. Group B did not receive the intervention until the end of the study after follow-up and therefore constitute the control group. Study participants were recruited from the clients and referrals of the CEPAs and the informal lay workers. Those referrals meeting the criteria were randomly selected into the group A or Group B. Each of the CEPAs follows, at some level, an average of 500 families a year and the volunteers report similar contacts throughout their counties. Assuming that each family has at least one female 40 and older, that provided us a total study population of 3,000 women or a potential of 1,000 prospects per county.

Given that the overall goal of this intervention is to increase the number of African American women who participate in screening for breast cancer, we hypothesize from a quantitative perspective, that at follow-up: 1. Knowledge of breast cancer risks, prevention, and detection will increase among women in Group A (the intervention) from a baseline by 30 percent and by 10 percent among women in Group B; 2. The percent of women who have had a clinical breast examination within the last year will increase by 40 percent in Group A and by 20 in Group B; 3. The percentage of women in who have had a mammogram within the past year will increase by at least 30 percent in Group A and by 15 percent in Group B.

The intervention delivered to Group A is illustrative in Figure 11 below. Research instruments for this Phase of the study include: Contact sheets; computer generated list of random numbers for study group assignment and protection of identity; personal information questionnaire includes demographics and questions about breast cancer knowledge, health behaviors and practices including herbal and other folk remedies; color-coded response to track mammogram obtainment by county and group assignment; list of talking points on the information each participant in Group A must receive about breast cancer. Surveys One (pre-intervention) and Two (post-intervention): In order to detect and quantify the effects of the intervention in terms of the degree of change, short, 5-6 item pre-/post surveys are being orally administered to both groups. The survey breast cancer permission to discuss breast cancer and beliefs about seriousness of the disease, personal risks, prevention capability, efficacy of breast self-exams and mammograms, personal intent towards screening practices. The post-intervention survey asks

the same questions as the pre- survey. The follow-up survey o ask the same questions with the exception of the first (permission) question which will be deleted, and with the addition of a response question, "Since our previous conversation about breast health and breast cancer, have you obtained or attempted to obtain a clinical breast examination or mammogram?"

Figure 11:The Intervention Description (Phase Three)

1. Prepare prospect list
2. Recruit study participants
3. Assign ID numbers

Group B (the Control):

4. Contact prospects and set-up group session;
5. Conduct session: consisting of administering the PIQ and Survey 1 distribute breast cancer brochures allowing reading time administer Survey 2 distribute referral packages, thanks participants and give incentive.

Group A (Intervention):

4. Contact prospect; explain study and set-up in-home interview;
5. Conduct intervention: obtain signed consent, administer Survey 1; conduct conversation about breast cancer; review brochures allowing participant time to read and ask questions; demonstrate breast self examination; administer Survey 2; give and explain response card and referral material for mammography sites and information hot-lines; give cash incentive;

6. Conduct 30-day follow-up:

Has participant obtain mammogram? Yes \Rightarrow intervention ends;

No but has appointment \Rightarrow encourage and inquire about any transportation or other access problems; No and has no appointment \Rightarrow repeat step 5 including all instruments except the PIQ repeat step 6: Has participant obtained a mammogram? Yes \Rightarrow intervention ends; No but has appointment \Rightarrow encourage and inquire about transportation needs. Repeat Step 6; No and has no appointment \Rightarrow inquire about any concerns participants has about mammography and interest in continuing in the study - if no interest, study ends - interested set-up third and final visit, encourage participant to invite family and friends

Repeat Step 5 \Rightarrow Repeat Step 6, the final follow-up.

Step 7 - conduct random telephone survey of participants who do not get mammograms to assess intervention process and intentions regarding breast cancer screening.

Targeted Sites: Profiles

Talbot County

Statistics (2000 Census)	Number	Percent
Population:	6,895	
White		38.1
African American		61.6
Hispanic origin		1.3
Income:		
Per Capital Income	\$15,385	
Median Household Income	25,356	
People of all ages in poverty		24.2
Whites		8.7
African American		34.7
Persons 25 & older completing high school:		
White		75.7
African American		41.8
Age:		
18-64		61.4
65 and older		14.4

Source: Georgia Facts and Figures, University of Georgia College of Family and Consumer Science.

Marion County

Population:	7144	
White		
African American		34.1
Hispanic origin		5.8
Income:		
Per Capital Income	\$16,481	
Median Household Income	25,355	
People of all ages in poverty		22.4

Whites		16.5
African Americans		42.9
Persons 25 & older completing high school:		
White		62.0
African American		42.1
Age:		
18-64		61.1
65 and older		10.3

Source: Georgia Facts and Figures, University of Georgia College of Family and Consumer Science.

Schley County

Population:	3766	
White		
African American		31.3
Hispanic origin		2.4
Income:		
Per Capital Income	\$18,905	
Median Household Income	28,479	
People of all ages in poverty		19.9
%Whites below poverty		8.2
%African Americans below poverty		42.2
Persons 25 & older completing high school:		
White		63.4
African American		41.5
Age:		
18-64		59.6
65 and older		11.1

Source: Georgia Facts and Figures, University of Georgia College of Family and Consumer Science.

Findings:

Table: Participant Recruitment by Site (Total 373)

Marion County	Schley County	Talbot County
135	128	110

Table: Valid Surveys by Site (348)

Marion County	Schley County	Talbot County
125	123	98

Demographic Profiles as percentages of N:

Marion County Group A N = 52

Age group

M

Sg

D/Wd

Regular source of healthcare

Y / N

Family history breast cancer

Y/N/D

Heard of mammogram

Y / N

Mammogram status*:

Never/> 2

Reasons

Stated*

1/2/3/4/5/6

40-50

(9)

69 31

O/33/67

100 0

67 33

33/0/0/67/67/33

51-60
(20)

67 23

0/71/29

86 / 14

29 / 43

0/0/0/23/23/43

61&older
(71)

66 34

44/40/16

96 4

20 / 16

12/8/8/28/24/12

M=married, S=single, D/Wd=divorced or widowed

* Only those who never had mammogram or have not had one in more than 2 years

Some numbers will not equal to 100 percent since no responses were treatment as 0

Marion County Group B N= 83

Age group

M

Sg

D/Wd

Regular source of healthcare

Y N

Family history breast cancer

Y/N/D

Heard of mammogram

Y N

Mammogram status:

Never/> 2 yr

Reasons

Stated

1/2/3/4/5/6

40-50

(35)

80 20

24/59/12

100 0

65 0

0/2/0/7/5/23

51-60

(26)

60 40

27/47/26

87 13

47 7

7/7/0/20/13/33

61&older
(39)

71 29

18/64/18

73 27

36 0

21/9/9/32/37/37

Schley County Group A N=66,

Age group

M

Sg

D/Wd

Regular source of healthcare

Y/ N

Breast Ca. Family

History

Y/N/D

Heard of mammogram

Y/ N

Mammogram status*:

Never/> 2

Reasons*

Stated

1/2/3/4/5/6

40-50

(9)

100 /0

25/75/0

100/ 0

0 / 17

0/0/0/0/100/0

51-60

(24)

83 / 17

33/67/0

75 / 25

36 / 0

0/0/0/0/67/33

61&older

(67)

83 / 17

33/63/4

63/ 37

47 / 13

10/13/10/3/20/20

*

Schley County Group B N=57, percent

Age group

M

Sg

D/Wd

Regular source of healthcare

Y / N

Family breast cancer

History

Y/N/D

Heard of mammogram

Y/ N

Mammogram status:

Never/> 2

Reasons stated*

1/2/3/4/5/6

40-50

(24)

89/11

30/70

89 / 11

33/33

17/0/3/17/33/33

51-60

(41)

73 / 27

33/67/0

67 / 33

20/13

7/7/27/13/7/20

61&older

(35)

87/13

46/54/0

93/7

13/20

7/27/20/7/13

Talbot County. Group A N=48

Age group

M

Sg

D/Wd

Regular source of healthcare

Y/ N

Family history breast cancer

Y/N/D

Heard of mammogram

Y/ N

Mammogram status:

Never/> 2

Reasons stated *

1/2/3/4/5/6

40-50

(45)

29/ 71

18/41/41

76 18

65 18

18/12/6/6/24/59/12

51-60
(16)

83 17

33/33/34

67 33

50 17

17/0/0/33/67/17

61&older
(39)

87 7

27/20/47

60 20

47 7

27/20/7/67/7/7

Talbot County. Group B N=50

Age group

M

Sg

D/Wd

Regular source of healthcare

Y N

Family history breast cancer

Y/N/D

Heard of mammogram

Y N

Mammogram status:

Never/>2yrs.

Reasons stated*

1/2/3/4/5/6

40-50

(46)

83 13

39/43/13

83 22

35 13

4/22/17/9

51-60

(18)

44 66

0/44/66

67 33

56 22

0/11/0/11/57/44/22

61&older

(36)

83 17

2717/56

94 6

50 17

17/28/0/67/39/17

*1=don't know where to go; 2=don't believe increases survival chances, 3=don't believe at risk, 4=afraid, 5= can't afford, 6= never told to get a mammogram.

Objective 4: Evaluate the impact of the comprehensive intervention on breast cancer screening knowledge, attitudes, and practices by measuring these parameters at baseline, and following the intervention.

Study Participants by Group Assignment and County Site (Recruitment/retention)

County	Group A (intervention)	Group B (Control)
Marion	52	83
Schley	66	57
Talbot	48	50
Totals	166	190

Percent increases as verified by response cards for health provider: breast cancer knowledge, beliefs, and intent/practice at six-month follow-up of intervention group.

County	Knowledge		Beliefs		Percent change	Intent/practice*	
	Pre	Post	Pre	Post		Pre	Post
Marion	70	71	71	70.2	.02	0	11
Schley	47	100	98	84	.39	0	26
Talbot	38	48	32	60	.18	0	0

*Had mammogram or pending appointment

Percent increase as verified by response cards: breast cancer knowledge retention, beliefs, and intent/practice at six months of the control group.

County	Intent/Practice Post
Marion	.036
Schley	.09
Talbot	.04

Telephone follow-up to intervention group members for whom post intervention intent/practice was unknown

N=10 percent of study sample

County	Intent/practice (%) Mammo/Appt.	
Marion	3	5
Schley	6	10
Talbot	0	7.5

Most Frequently Stated Reasons for Not Getting Mammograms post-intervention.

1. Can't Afford it
2. Doctor did not advise it
3. Getting appoint difficult at convenient time for those whom don't drive
4. Fear – don't want to know if there is a problem

DISCUSSION/CONCLUSIONS

1. Summary of Interpretation of Ethnographic Findings

The findings of the ethnographic research indicate that rural African-American women diagnosed with breast cancer have developed a belief system that integrates traditional beliefs with those of biomedicine. These women have incorporated their terms and concepts they learned in treatment into their beliefs about cancer.

The most significant finding indicates that breast cancer beliefs strongly influence the use of medical care. Diagnosis of breast cancer is the most salient factor for predicting preventive behavior; it is the driving force toward positive shifts in beliefs about breast cancer. Before diagnosis, a majority of women in all research sites were "silent" about breast cancer in their cultural knowledge and behavior. Over 90% did not think about the disease or think they would get the disease. Over 65% did not discuss cancer with anyone. Most did not utilize any preventive resources. Almost 50% believed they had "no symptoms" meaning that they did not recognize symptoms before diagnosis. Some indicated that they did not seek help after they discovered that had a lump. A majority of the women discovered their breast cancer during a visit to the doctor for another reason.

At the point of diagnosis and subsequent medical treatment, their beliefs begin to change integrating more medical terminology that describes breast cancer. Cultural domain and explanatory modeling analysis suggests that most of the women now use medical terms for their symptoms, causes, and treatment for breast cancer. The meaning of these terms, however, often does not correspond to those of medical personnel. Nonetheless, this medicalization process results in an increased use of preventive care and increased level of communication about the disease, particularly with their husbands and children. Results strongly indicated that the women were more empowered to take control of their health after diagnosis. Although a majority of women believe that cancer is inherited and/or the environment causes the disease, once they have made a shift in beliefs toward a medical model of cancer and preventive care, they become more empowered and feel more in control of their future. Changes in beliefs produced positive shifts toward preventive behavior. Thus, cultural beliefs regarding preventive care are certainly a stronger factor for predicting use than access or affordability of medical care.

The variation in beliefs among sites was significant in terms of the prevalence of traditional beliefs regarding causes and treatments for breast cancer and in terms of perceptions of the disease. The women who live in the more isolated site, Savannah, have stronger beliefs in the use of home remedies for treatment (albeit never as a replacement for medical care) and they are the only ones who talked about their belief in the importance of "blood" for causing the disease. Their cultural domain for breast cancer was smaller than the other sites indicating that their knowledge is more bounded about breast cancer. This indicates a lower level of participation in and communication with medical institutions and personnel. These findings suggest that they are less likely to seek care or even discuss breast cancer with their family and support networks.

Another significant finding points to the importance of religious beliefs in the experience and coping with breast cancer. 90% believe that faith helped them survive the disease. All the women believe that God is working through the medical personnel. 64% believe that they would trust more in God to cure cancer than medical treatment indicating the importance of the integration of religion and medicine. Seventy-one percent believe that their faith will determine if they are cured and 64% believe that church members praying will cure cancer. In large measure, religious beliefs are an influential force for the increased use of medical care, especially after diagnosis. It increases trust in doctors and the medical system. Once preventive care is included in their cultural beliefs, its use appears to be increased.

These findings indicate that promotional programs aimed at changing beliefs need to conceptualize these complex issues as a process involving changing beliefs before diagnosis of breast cancer. The positive changes reported in this study can be used as a model from which to work backwards. Promotional programs can certainly assume that positive changes can occur and that changes in beliefs before diagnosis will save lives by increasing rural African-American women's use of preventive care. They should also consider the variation of beliefs in more isolated populations.

2. Intervention:

The following hypotheses were set forth regarding the outcomes of this intervention at one-year follow-up. Because this project took four years instead of the initial three to complete

preparations and implementation of the intervention time constraints and lack of funding, documented follow-up (response cards from mammography facilities) only been done at six months for the intervention group. Therefore statements made herein are based on data on file at six months and telephone follow-up of a random sampling of the intervention group.

1. Knowledge of breast cancer risks and prevention among women aged 40-65 and older will increase by approximately 30%.
2. At follow-up, the percentage of women aged 40-65 and older who have had a clinical breast examination within the past year will increase by at least 20%.
3. At follow-up, the percentage of women aged 40-65 and older who have had a mammogram within the past year will increase by at least 20% and will be at least 50%.

Since verifiable data of mammography is not available past six months, an assessment would be inconclusive at this time, however, progress has been made, particularly in Schley County where the percentage increase is at 26 percent at six months and an additional 10 percent as indicated by phone follow-up to participants. The lay health worker for Schley County was a Breast Cancer survivor, which may have impacted her success in getting participants to comply with the recommended screening practices. A significant finding in this study was that the majority of participants had a regular place for healthcare, but of those who had never had a mammogram, their health provider had not told them to get one or had not put significant emphasis on the subject. The variable locus of control for examined in this study using the question, "No matter what I do, if I am going to get cancer, I will get it". Eighty two percent of respondents agreed with this statement irregardless of age or education. This suggest that most of our participants have an external locus of control, i.e., they depend on persons other than themselves regarding certain issues, in this case getting medical test.

The method of breast health information delivery used in this study appears to be an effective method for reaching rural African American women. The key seems to be that the delivery has to be continuous, interpersonal, and implemented from various channels including the medical provider.

KEY RESEARCH ACCOMPLISHMENTS:

- ❑ Validated training protocols and manual for ethnographic study with African American women.
- ❑ Large database of audiotaped interviews with African American women on health issues other than and in addition to breast cancer.
- ❑ An in-depth assessment of beliefs and practices regarding health practices for rural, southern, African American women.
- ❑ A training curriculum for training lay people to assist in community-based research.

REPORTABLE OUTCOMES:

1. Manuscripts, Abstracts, Presentations:

Journal Article:

Williams, MP, Brown, L. Hill, CE. Schwartz. D (2001). *Promoting Early Breast Cancer Screening: Strategies with Rural African American Women*. Amer. J. Health Studies 17(2): 65-74.

Abstract

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2. Informatics such as databases and training models

African American Female Breast Cancer Survivor Database

Training manual for research

Training guide for lay health educators

3. First time African American women with baseline mammograms

4. Pilot-test breast health promotion program for rural

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APPENDICES:

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Introduction

Death rates are far too high from diseases that are preventable, or if contracted, have a high probability of being cured if detected during early stages of development. Breast cancer is one of those diseases (NCHS, 1996; Horton, 1992). It is the most common cancer in American women: one in every 10 women will develop breast cancer sometime in her lifetime (Miller et al., 1996). While research findings and professional organizations support regular breast examination and mammography as effective screening methods for early stage breast cancer (CDC, 1994; Miller et al., 1996), surveys indicated that 44 percent of white women, 51 percent of Hispanic, 52 percent African American, and 54 percent of Asian American reported not having a mammogram according to American Cancer Society guidelines for their age group. The highest death rate from breast cancer was reported among African American women (National Women's Health Network, 1996). This higher mortality rate is thought to be due largely to late stage diagnosis. While reasons are suggested for this phenomenon, e.g., lack of knowledge, failure of health provider to initiate screening procedures, costs, culturally inappropriate approaches (Farley & Flanery, 1989; Caplin, Wells, & Haynes, 1992), empirical research is limited.

Despite the documentation of the higher morbidity and mortality of breast cancer among African American women, there is limited information published on effective interventions to increase

breast cancer screening among this population. Black women can be members of heterogeneous cultural groups, many with mixed ancestry including individuals with Caribbean, Indian, and European lineage. Marked differences in acculturation exist and contribute to the diversity of their health. Therefore generalizations that create health profiles for these women are dangerous because exceptions to the rules are numerous (Nyamathi et al., 1993). However, relatively little research has been devoted to identifying effective strategies for increasing breast cancer screening rates among African American women of varying cultural and intra-cultural backgrounds. Social scientists and health communication researchers have held that if health promotion campaigns are to influence the audience as intended, they must be culturally, demographically, and geographically appropriate (Williams, 1996; Atkins & Freimuth, 1989; McLeroy et al., 1988). Research defining the variable of cultural sensitivity is also very limited regarding interventions that target diverse populations.

Research examining the efficacy of health promotion appeals, content, and channels of delivery regarding breast cancer has also been very limited in public health research. A number of factors frustrate the formulation of effective campaigns to promote healthy behaviors and practices. First, health promotion campaigns usually exhort people to change deeply rooted beliefs and behaviors that have been continually reinforced over a lifetime, and perhaps throughout preceding generations. Secondly, health promotion information and recommendations are traditionally based upon epidemiological findings that do not often include a broad, in-depth assessment of culturally driven behaviors that are especially prevalent in multi-ethnic and multi-cultural societies. Further, virtually all health promotion message approaches are based on cognitive/behavioral theories of communication that assume that all people view and interpret situations similarly (Fishbein & Ajzen, 1981; Kreps, 1988; Greenberg et al., 1988). However, health and disease may mean different things to different people. McLeroy and colleagues have suggested extension of the traditional cognitive framework to include interpersonal processes, institutional factors, community factors, and public policy issues as well.

Across the United States, health promotion interventions are using strategies involving community health worker or lay advisor (helping healers) programs to reach traditionally underserved populations (Parker et al., 1998; Blumenthal et al., 1989). The difference between these programs can be explained on a continuum of formal to informal helping (Eng, Parker & Harlan, 1997). The formal end of the continuum consists of the paraprofessional/outreach worker who is a paid employee of some community-based agency or organization. The informal end of the continuum is that community person who always seems to be there volunteering to help individuals and community efforts. Both of these strategies involve identifying individuals, within existing social networks of the targeted audience, who other network members trust and regularly turn for social support. While several studies report the effectiveness of the informal model of this type worker to deliver breast health messages, particularly in rural areas, few reports evaluate the impact of utilizing the formal model for such activities. In an effort to expand the knowledge base on health promotion and breast cancer and related delivery systems, the Morehouse School of Medicine is conducting this Breast Health Belief Systems Study (BHBS).

Project Background and Conceptual Framework

The BHBS is one of several community-based projects in the overall health promotion and disease prevention program at the Morehouse School of Medicine (MSM) in Atlanta, Georgia. Administratively, the study is housed in the Department of Community Health and Preventive Medicine, which historically has functioned as the bridge between the school and the community. Our Breast Health Belief Systems Study was designed to address the saliency of beliefs about breast cancer for constructing effective health promotion messages for African American women. It assumes that the first step for designing meaningful communication about breast cancer preventive and help-seeking behavior is to explore a group's belief system regarding the disease. Beliefs are defined as the basic units of thought that establish a relationship between at least two entities and are culturally driven (Kreps & Thornton, 1984). For the purpose of this study, culture is defined as a set of interlocking cognitive schemata that construct and give meaning to what people do in their everyday lives. These schemata are transformed within specific social environments, and are constrained by the economic and political context of a specific group. Kreps and Thornton also offer organizing principles that can affect meaningful health communication: world view; socialization; and interactions with social organizations such as schools, churches, law enforcement, mass media, and the health care system. Empirical as well as historical evidence indicates that religion is a significant factor in the lives of African Americans, particularly women. Further, religion plays a central role in African American women's efforts to cope with a wide array of problems including illnesses (National Survey of Black Americans; Levin & Taylor, 1998; Neighbors et al., 1983; Chatters & Taylor, 1989; Taylor et al., 1999; McAdoo, 1995) and they maintain a deeply rooted faith in God and in the fundamental values of particular faith traditions (Mattis, 2001). Jahn (1961) explains that from an Afrocentric perspective, it is not possible to separate theology from medicine or vice versa without violating the entire worldview of the group. Belief structures, composed of values and attitudes, are considered cultural knowledge (Quinn & Hollard, 1987; Ashante, 1988). Understanding and integrating cultural sensitivity into the design of a program personalizes the message, thereby increasing the likelihood that the target audience will understand and accept the recommendations. Since beliefs about breast cancer are a product of both personal experiences and information obtained through interactions with others (either interpersonally or through media), not all members of a group will have identical sets of cultural knowledge. Delineating variations in beliefs is an important design element to more effective intervention strategies. For example, Matthews et al. (1994) found that African American women in rural North Carolina draw on multiple sources of knowledge in order to come to terms with their breast cancer.

Building on these literature findings and our own research experiences, an initial conceptual framework was developed, which postulates that a breast health approach that proceeds from and responds to specific belief systems among low-socioeconomic, African American women, will motivate increased compliance to recommended cancer screening schedules, and positive shifts in knowledge and attitudes about the disease.

Method/Approach

The expected outcome of this study is the development of a model community-based intervention designed to educate and motivate rural African American women to adopt good breast health screening practices. The study consists of three Phases: One - An ethnographic survey of women who have or have had breast cancer to determine intra-cultural variations in the variety, scope, and depth of beliefs and practices (before and after diagnosis/treatment) regarding breast cancer; Two - Use of the analysis of data gathered from Phase One to develop an interpersonal, target-specific breast health promotion program for women with no known breast cancer and who have not had a mammogram in the twelve months (or 24 for those 49 and younger) preceding participation in the study; and, finally, Phase Three - implementing and measuring the effectiveness of the breast health intervention and its delivery strategies. Disciplines involved in this study include faculty and students from gerontology, health communications, anthropology, sociology, public health, home economics, theology, and nursing. Collaborating institutions and agencies are Georgia State University, Fort Valley State University, Albany State University, Savannah State University and the Older Americans Council of Middle Georgia. Phases One and Two have been completed. Phase Three, is nearing completion. The following is a description of the conceptualization, development, implementation and findings to date from this study.

Our Breast Health Belief Systems Study involves researchers, community members, and practitioners in a joint process aimed at meeting both research and intervention objections. This process bares similarities to the Participatory Action Research approach (PAR) (Israel et al., 1994) and the Braithwaite-Lythcott (1989) model of community organization for health promotion. Both allow the insiders view of life to be considered in health education program planning. Adapting elements from these approaches, this project involves the use of two research components: a single case study design in Phase One (ethnographic survey) which allows for an empirical investigation of a contemporary phenomenon (under utilization of breast cancer screening methods by African American women) within its real-life context and from the perspective of the effected group; and a quasi-experimental design in Phase Three (the intervention) utilizing qualitative and quantitative methods.

Establishing the Research Team: Senior or graduate students from Historically Black Colleges and Universities near our study sites were trained and utilized as research assistants. These research assistants conducted the Phase One in-home interview of breast cancer survivors. Major criteria for selection of the research assistants were that they live in or near one of the study communities, have a history of regular involvement in local community-based events, and a demonstrated interest in community welfare. A faculty preceptor from each school assumed the responsibility for selecting students and the on-site supervision of the student research assistants. These criteria provided a number of advantages: cultural and geographic familiarity, inter-institutional collaboration, involvement of health-related students in community-based health promotion (Hatch & Lovelace, 1980), and cost effectiveness in terms of controlling travel expenses in connection with the ethnographic analysis. Both the informal and formal models of lay health workers, as described previously in this article, were part of our research team. Informal lay health workers, trained on how to recruit study participants, assisted in Phases One and Two with pilot-testing the instruments and recruitment of study participants. Formal lay

health workers assisted in Phase Three with study participant recruitment and delivery of the educational intervention.

Unique to this research team is the Cooperative Extension Service. Though better known for its agricultural focus, the extension service also includes community development programs including health education. One of our HBCU partners, Fort Valley State University Extension Program, operates in 13 rural counties in Georgia and is a longstanding trusted institution among the black community. The Fort Valley Program employs paraprofessionals called Cooperative Extension Program Assistants (CEPA) who are usually indigenous to the community in which they work. Supervised by home economist, their responsibilities include in-home economic and health education activities. Cooperative Extension Program Assistants functioned as formal lay health workers in Phases two and three of this study.

History and Context of Rural Georgia: The BHBS study takes place in middle and southern Georgia in thirteen counties in Phase One and three (3) counties in Phase Three. Most of these counties generally rank lower than their urban counterparts on conventionally used, measurable indices of quality of life, i.e., poverty, low population density, large geographic expanses, lack of human service-related resources and negative capital flow to urban areas. Findings from a previous MSM breast cancer study (Blumenthal et al., 1989) in Georgia suggest that far too many African Americans do not participate in early detection for breast cancer, even in areas where tests are low or no costs. This study found that only 30 percent of inner city and 20 percent of rural women were likely to receive screening, according to guidelines published by the American Cancer Society. Thirty-six percent of those surveyed did not feel the urgency to get mammogram or pap smears on a regular basis.

Our research objectives dictate that these counties fall within at least one of three categories: physically isolated area of extreme poverty, a rural area that provides access to a metropolitan center, and a poor coastal area that feature a wide range of intra-cultural variations including one with potential Gullah (practice of traditional West African folkways) influences. In Phase One the thirteen counties are reported in geographic groupings or public health districts: Albany for the southwest, Macon for middle Georgia, and Savannah for the southeastern and coastal regions. The African American population in these counties is 40 percent or greater. All three of these areas contain counties, which fall into at least one of our site categories. The Savannah district is the site where more small pockets of residents who adhere to some practices of West African folkways. Because of demographic characteristics, it was assumed that these three geographical sites would provide variation in the samples for exploring the study's assumptions.

Phase One: Ethnographic Survey. Seventy-five women with a current or past diagnosis of breast cancer were targeted for the ethnographic survey. The rationale for interviewing women with a history of breast cancer was to make a pre and post diagnosis comparison of beliefs, knowledge, and practices, then work backwards to use these findings for the development of our intervention study. Three assumptions guided the selection of research sites and the collection of ethnographic data. They were: women from isolated rural communities are less likely to seek preventive biomedical care; women from rural communities with access to complex urban systems are more likely to seek preventive biomedical care; and cultural beliefs about preventive

care for breast cancer and for health problems in general are stronger persuasive agents than access to, or affordability of, medical care services.

The methods used in our study were in-home, face-to-face interviewing using an interview schedule; free listing to delineate cultural domains and pile sorting to delineate shared cultural categories for breast cancer. These techniques also allowed us to understand how breast cancer beliefs are organized in the mind of respondents and to provide a baseline for discovering variation in cultural knowledge in the three research sites.

Data collected were analyzed via focused coding methods that utilize the constant comparison approach to develop relevant themes (Patton, 1990; Straus & Corbin, 1990). The interview schedule questions were designed to elicit descriptive information for determining the Explanatory Models (EMs) and decision-making processes for breast health disorders. Collected in narrative form, EMs link beliefs and behavior within the context of people's experience the words of the respondent. They provide a person having breast cancer with a causal explanation for the disease. During the in-home face-to-face interview, the respondents were asked about their pre and post diagnosis beliefs about breast cancer and related problems. Each interview was audiotaped, transcribed and compared to the written narrative to verify that the participants' perspective was accurately captured. Each narrative contained the following variables: causes of breast cancer; symptoms of breast cancer; alternative treatment, definitions of breast cancer; expected outcomes, and attitudes toward breast cancer providers.

From these data an explanatory model was constructed for each woman in the sample. They were subsequently aggregated for each research site. Decision modeling focused on discovering and testing individual's criteria for making treatment choices. Shared standards for decision making about health behavior were used to construct a model that predicted the different treatment options that people can be expected to choose. People's knowledge structures and conceptions of illnesses are inextricably related to their illness responses, and consequently, to their decision making processes about treatment alternatives. The specific data that was systematically collected to construct decision models include the following variables: constraints of decisions about breast cancer treatment choice, intuitive rules for making decisions, rationale for making choices, and sequence of choices of treatment.

Study Participant Recruitment: Because cancer databases for the state of Georgia were incomplete for several of the counties our study targeted and the challenges encountered in gaining access to existing files on demographically similar counties, we use a grass roots effort to develop our own registry of African American breast cancer survivors. Utilizing existing relationships between Morehouse, local medical facilities, health departments, professional associations, and community-based agencies/organizations, representatives were contacted for assistance with publicizing our study and recruiting participants. Additionally, flyers were disseminated at medical facilities, churches, community centers, senior centers, grocery stores and other common gathering places for African American females. Cancer support groups, home health agencies, and medical facilities, particularly cancer treatment centers, were the most helpful in this regard. While this route proved to be more laborious than accessing existing registries, the effort was worth the time and energy because it provided more opportunities for

direct community involvement and proved to be an excellent learning experience for staff and students.

The targeted sample number was 75 (25 from each site). The following criteria were used for selecting respondents: Low SES (\$17,000 yearly household income or less); 40 years old and older, and lived in rural areas for past 15 years. Once identified, our lay health workers recruited participants into this study. The lay health workers administered the personal information questionnaire and referred each respondent to the research assistants who obtained the informed consent and conducted the interview. Upon completion of the interview, participants received a cash incentive.

Phase One Results: A total of 64 respondents were interviewed. Table 1 summarizes the demographic profiles for each site.

<Table 1>

Ethnographic findings only partially supported the assumptions of our ethnographic survey. For the first assumption, the findings indicate that women who live in more isolated sites sought preventive care only slightly less often than those women at the least isolated sites. Women who have more physical access to complex urban systems were no more likely to seek preventive medical care than the women in the other two study sites. The ethnographic findings, however, upheld the third assumption that cultural knowledge about preventive care is strong persuasive agents for seeking medical care services for breast cancer. While costs and transportation were problematic for some respondents, particularly those who did not drive, these factors were not as persuasive as cultural beliefs.

Pre-Diagnosis Beliefs: Ninety-five percent of participants did not think about the disease; 65 percent did not discuss it with anyone; 50 percent believed they had no symptoms. The indications are that few symptoms appeared in this group or symptoms were not recognized, both significant issues to explore in future research. Some did not seek help immediately after finding a lump. Seventy-five percent had regular doctors to whom they made regular visits. While most doctors' offices displayed information about breast cancer and other diseases, participants reported receiving little counseling on the importance of regular screening. Those participants who participated less often in regular breast cancer screening were most often those who were: under 45 years of age, regardless of family history, no regular doctor, had less than a high school education, and those over 65 regardless of whether they had a regular doctor or not.

Post-Diagnosis Beliefs: At the point of diagnosis and subsequent medical treatment, the women's beliefs changed to: use of medical terms learned from their experiences with breast cancer for their symptoms, causes and treatments. However, the distinction between diagnostic procedures and treatment was not clearly understood. Nonetheless, this medicalization process results in an increased use of preventive care and an increased level of communication about the disease. Terms and concepts learned in their diagnostic and treatment experiences were framed within a religious context. More than 90 percent believe that faith helped them survive the disease. Belief that God works through doctors increased trust in the medical system and demonstrated a truly integrative belief system between religion and medicine. This finding is consistent with studies previously cited in this article regarding the role of religion in the lives of African American women. All women believed that God works through the medical providers;

medical providers who demonstrated a spiritual component to healing were most trusted and more likely to receive compliance from the patient. These findings verify that the medical setting is a critical context for increasing health promotional messages and that breast-health messages personalized for African American women need to be transmitted to medical personnel.

Site Variations: To date, there appears to be more similarities than significant variations between the sites. The variations in cultural knowledge and behaviors appear greater between the Savannah sites and the other two, Albany and Macon. However, it must be noted that some of this variation may result from the smaller sample size in the Savannah sites. For example, in response to the question "Who did you first talk to about your breast cancer?" Albany Health District: sisters, daughters, doctors, husbands, female friends; Savannah: older female relatives, doctors, husbands; Macon: husbands, doctors, other family. Friends, ministers, and co-workers were the least mentioned first-talk choices across sites. This finding is consistent with Dressler's studies of rural African Americans, which stressed the extended kin network more than friends as protective against depression. Findings from the Save-our-Sisters project in rural North Carolina, show that support from female peers has been a significant predictor of accepting recommendations, following through with scheduling, and keeping appointments with mammography, even after controlling for physical health status, age, education type of insurance and source of care (Eng, Parker & Harlan, 1997). While all of the study participants wanted others to pray in church for their recovery, the Savannah site participants were more likely to prefer private prayer in their homes. Additionally, as seen in Figures 1, participants receive information about breast cancer from a variety of sources. Figure 2, however, illustrates the most trusted sources and here some notable differences between sites are seen. These between site variations suggest possible differences in intervention strategies.

<Figure 1>

<Figure 2>

Our findings also suggest that the quality of advice received either promotes visiting a doctor or trying other treatments first, including the length of time she delays visiting a physician. Social influences through informal networks are pertinent for breast cancer screening. In summary, tentative decision models for help seeking behavior were constructed from the ethnographic data (Figure 3). Criteria were selected based on the findings of the explanatory modeling and the cultural domains for symptoms, causes, and treatment.

<Figure 3>

The decision tree generated from the overall sample suggests the criteria affecting the decision-making process of African American women to go to the doctor and reduce diagnosis delay. This model is viewed as a hypothesis only for seeking medical care. This decision tree for going to a doctor has not been yet tested on a second and third sample and is, therefore, not a predictive model of the help-seeking process of African American women regarding breast cancer. It does, however, illustrate the preliminary criteria involved in going to a doctor for this sample.

Phase Two: Formulation of the interpersonal Message and Diffusion Strategies.

Methods: Several emerging communication models, e.g., Witte's (1995) Persuasive Health Message (PHM) framework, have expanded the purely cognitive/behavioral approach to health promotion by integrating cultural, environmental, knowledge, attitude, and belief variables into message development. Utilizing these models and data from population profiles for each of our

study sites and common themes that emerged from our ethnographic survey in Phase One, we developed a breast health message that is uniquely personalized to our study population. The content for the health messages was taken from publications of the National Cancer Institute and the American Cancer Society and adapted, as needed, to an eighth-grade reading level. Messages included basic information about breast cancer such as statistics, risk factors for low-income and African American women, the diet/nutrition/stress information, and the importance of early detection, screening guidelines and procedures, and information resources. The presentation of these messages is described below in Figure 4, the Intervention.

A diffusion strategy deals with how information is communicated through certain channels over time among members of a social system. Our strategy utilizes elements from the Community-based Diffusion Model (1987) and the Braithwaite-Lythcott Model (1989) for community organization for health promotion. Both models recommend an understanding of the role, patterns of use, and the impact of the local, mainstream health care systems such as private physicians, neighborhood clinics, hospital emergency rooms, and other health care resources. For example, since one of our study sites included counties situated along Georgia's Sea Island coast, we anticipated that some respondents may practice folkways handed down from their west African ancestors and may obtain advice from complimentary health providers such as herbalists and folk healers. "For members of a target community who continue to hold traditional health beliefs, it will be more effective to fit new health information into the old frame of reference rather than to dismiss traditional beliefs as ineffective or superstitious" (Ashante, 1988).

Important to the diffusion strategy is who delivers the message. The messengers for our intervention are lay health workers selected because of their position of trust and support giving within the social networks of the study population. Both the informal and formal models of lay health workers are used in this phase of our study. Our formal model utilizes Cooperative Extension Program Assistants (CEPA) who are paid employees of the Cooperative Extension Service. These individuals have been trained to work directly with county extension personnel in assigned programs of nutrition, agriculture, family services, youth development, and health promotion. A CEPA provides clients with direct assistance through home visits and/or other gatherings. Most have a high school education supplemented by in-service education in the fields of home economics, agriculture, or food service and nutrition. Our informal lay health workers are volunteers in a community center.

Lay health workers were trained by the study's principal investigator (a health educator and clinician), a co-investigator (a health communications specialist) and a registered nurse. The training curriculum included: providing a clear understanding of why the study was being done, discussions on each of the topics in the health message, demonstration on how to perform the breast self examination, preparation of the participant prospect list, selecting study participants, confidentially, data collection, recording keeping, making referrals, following research protocols, and delivery of the intervention. Nine talking points are highlighted as a guide for the information that each lay health worker must cover during the intervention. However, the lay health worker has the liberty to adapt her presentation of the information to the communication type most comfortable to the participant. Both the message and delivery were pilot-tested among demographically similar women living in rural communities not targeted by the proposed research. Role-plays were used to provide opportunities for hands-on learning and evaluation of

the trainee's ability to implement the intervention. Technical support and remedial training occurs on an as-needed basis throughout the implementation.

Intervention Development/Description: A breast health information and promotion intervention has been developed that is uniquely personalized for our study population. The presentation of this intervention is illustrated below:

Figure 4: The Intervention Description (Phase Three)

1. Prepare prospect list
2. Recruit study participants
3. Assign ID numbers

Group A (Intervention): 4. Contact prospect; explain study and set-up in-home interview 5. Conduct intervention: obtain signed consent, administer Survey 1; conduct conversation about breast cancer; review brochures allowing participant time to read and ask questions; demonstrate breast self examination; administer Survey 2; give and explain response card and referral material for mammography sites and information hot-lines; give cash incentive; 6. Conduct 30-day follow-up: Has participant obtain mammogram? **Yes** \Rightarrow intervention ends; **No but** has appointment \Rightarrow encourage and inquire about any transportation or other access problems; **No and has no appointment** \Rightarrow repeat **step 5** including all instruments except the PIQ **repeat step 6:** Has participant obtained a mammogram? **Yes** \Rightarrow intervention ends; **No but** has appointment \Rightarrow encourage and inquire about transportation needs **Repeat Step 6;** **No and has no appointment** \Rightarrow inquire about any concerns participants has about mammography and interest in continuing in the study - if no interest, study ends - interested set-up third and final visit, encourage participant to invite family and friends **Repeat Step 5** \Rightarrow **Repeat Step 6**, the final follow-up. **Step 7** - conduct random telephone survey of participants who do not get mammograms to assess intervention process and intentions regarding breast cancer screening.

Figure 4 continued,

Group B (the Control): 4. Contact prospects and set-up group session 5. Conduct session: consisting of administering the PIQ and Survey 1 distribute breast cancer brochures allowing reading time administer Survey 2 distribute referral packages thank participants and give incentive.

Six women indigenous to the population have been trained as lay health workers to recruit study participants and to deliver the intervention. Utilizing this approach has several advantages: it piggybacks on a well-established community-based agency with ongoing, structured relationships with the targeted communities. Most importantly, it leaves the community with

members who have more skills and knowledge about breast cancer and an implementing health promotion campaign to promote early screening practices.

Phase Three: Delivery of the Intervention. Study Participant Description and Selection.

Intervention sites include one county in each of the study sites, which meets the aforementioned study site selection criteria. The study sample consisted of two groups, A and B. Criteria for selection as a member of the study includes the following: African American female aged 40-65; current resident and native of target community; no history of breast cancer; no history of breast surgery; no history of mammogram in the 12 months preceding the study (women 50 and older) and 24 months (women less than 50). Group A receives the intervention. Group B does not receive the intervention until the end of the study after follow-up and therefore constitute the control group. Given that the overall goal of this intervention is to increase the number of African American women who participate in screening for breast cancer, we hypothesize from a quantitative perspective, that at follow-up: 1) Knowledge of breast cancer risks, prevention, and detection will increase among women in Group A (the intervention) from a baseline by 30 percent and by 10 percent among women in Group B; 2) The percent of women who have had a clinical breast examination within the last year will increase by 40 percent in Group A and by 20 in Group B; 3) The percentage of women who have had a mammogram within the past year will increase by at least 30 percent in Group A and by 15 percent in Group B. Research instruments for this phase of the study include: personal information questionnaire includes demographics and questions about breast cancer knowledge, health behaviors and practices including herbal and other folk remedies; color-coded response to track mammogram obtainment by county and group assignment; list of talking points on the information each participant in Group A must receive about breast cancer. Surveys One (pre-intervention) and Two (post-intervention): In order to detect and quantify the effects of the intervention in terms of the degree of change, short, 5-6 item pre-/post surveys are being orally administered to both groups. Survey questions seek to capture beliefs about seriousness of the disease, personal risks, prevention capability, efficacy of breast self-exams and mammograms, personal intent towards screening practices. The follow-up survey asks the same questions with the addition of a response question, "Since our previous conversation about breast health and breast cancer, have you obtained or attempted to obtain a clinical breast examination or mammogram?"

Summary/Discussion

A breast health promotion intervention has been developed and personalized for a rural, southern, African American audience. The study is now in Phase Three in which 600 participants, 300 experimental and 300 controls, are being recruited as participants. While it is too early to draw conclusions on the effectiveness of the approaches used in this study, this article has presented some insight into common issues considered important in the development and implementation of a target-specific, breast cancer prevention and screening program.

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Breast Health Belief Systems Study

Morehouse School of Medicine

Training Manual

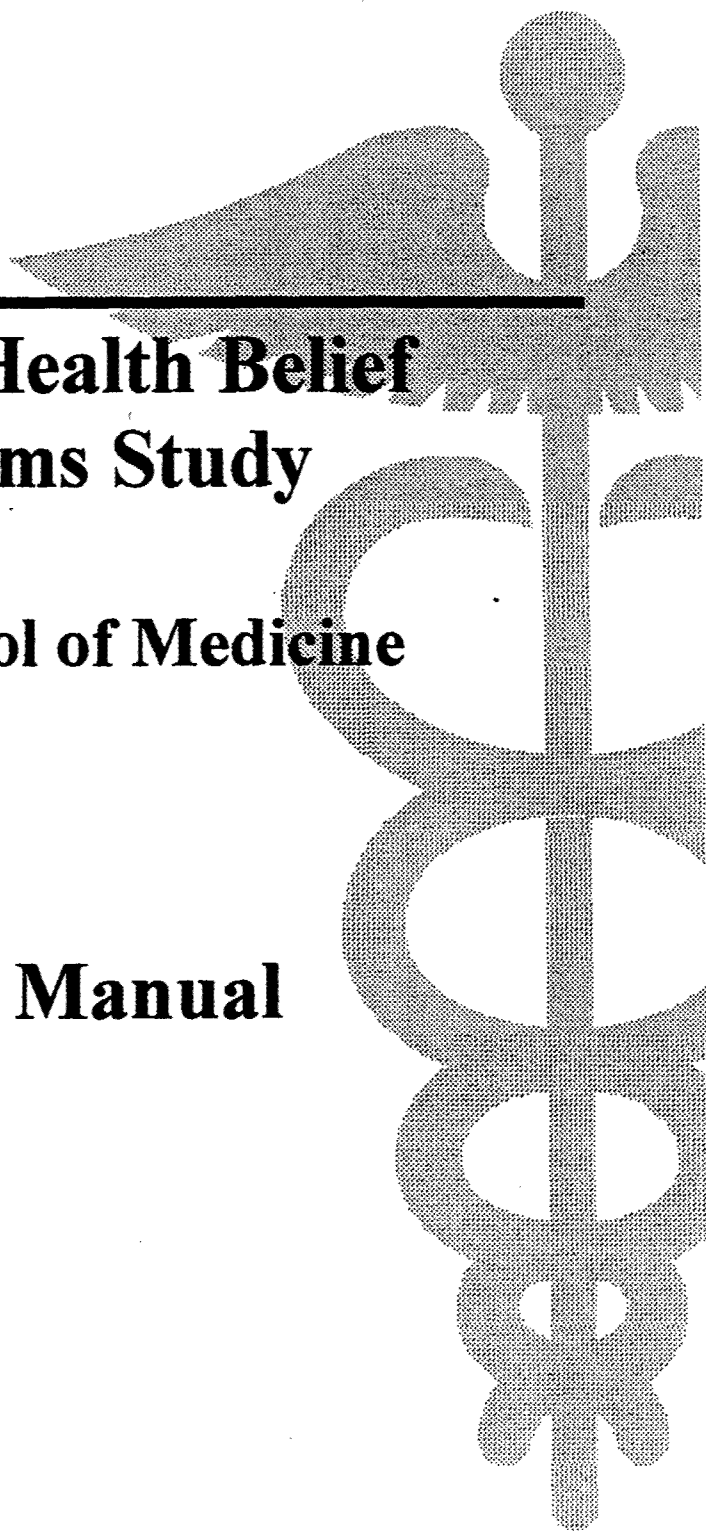


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PROJECT PERSONNEL

Dr. Mary Williams, Principal Investigator
Department of Community Health/Preventive Medicine
Morehouse School of Medicine
Atlanta, GA 30310
(404) 752-1626

Dr. Carole E. Hill, Co-Investigator
Department of Anthropology and Geography
Georgia State University
Atlanta, GA 30303
(404) 651-1764

Larry Brown, Co-Investigator
Department of Community Health/Preventive Medicine
Morehouse School of Medicine
Atlanta, GA 30310
(404) 752-1741

Dr. Ella Hammond Sims, Faculty Advisor
Department of Sociology
Savannah State University
Savannah, GA 31405
(912) 356-2935

Dr. E. Sherman, Faculty Advisor
Department of Sociology/Social Work
Albany State University
Albany, GA
(912) 430-4903

Dr. Clarence Willams, Jr, Program Coordinator
Fort Valley State University
Fort Valley, GA
(912) 825-6268

John Smith, Program Coordinator
Morehouse School of Medicine
Atlanta, GA 30310
(404) 752-1973

PROJECT DESCRIPTION AND GOALS

This project is called the Breast Health Belief Systems Study. It is a research project being conducted by the Morehouse School of Medicine with Georgia State, Savannah State, Albany State, and Fort Valley State universities. The main goal of this project is to obtain ideas and information that will be developed into a health education program to help reduce how often Black women get breast cancer and increase the chances of those who get it of being cured.

Although all women are at risk of getting breast cancer, the problem is that when Black women get cancer they are often seen late in the disease. Many reasons have been given for this and some things have been tried to change this outcome. But we still see more Black women with more advanced disease than other races. This suggests that more attention needs to be paid to early detection, good information, and access to services. Additionally, the planners of this study believe that culture and beliefs may also be major factors in how information is used and health promotion is practiced. In order to develop this health education program we will be involved in three activities:

1. Interviewing women who have a diagnosis of breast cancer.
2. Information gained from these interviews and other sources will be used to develop our health education program.
3. Once the health education program is developed, we will then put on workshops and pass out information in various community facilities and in some cases, in people's home about breast cancer.

PURPOSE OF INTERVIEWS

The interview is very important because we feel that the best way to get better information about Black women and breast cancer is to talk to those people who have experienced it. This interview will allow you to tell your story, what you knew about the disease, how you sought help, what advice you would give to other Black women about breast cancer and so on.

You will be one of 75 women from three counties in Georgia who will participate in this study.

ROLES AND RESPONSIBILITIES OF AN INTERVIEWER

I. Be familiar with the purpose and importance of the project so you can answer questions about the project.

The women we interview are called **Respondents**. These Respondents want to be heard and are usually happy that they are given an opportunity to talk. They are often willing to share their thoughts if they are convinced that their responses will be of some help to others. If you, as an interviewer, believe that the information obtained from the survey is important, your tone and manner will convey that importance to the Respondents.

II. Know how to confront problems and less-than-ideal circumstances "in the field."

Most problems will be minor and can be handled as they occur. For example, should an unexpected emergency (i.e. car problems, etc.) result in the delay or cancellation of a scheduled interview, be responsible enough to call and inform the Respondent.

More serious problems (i.e. your inability to fulfill your role as an interviewer) should be brought to the attention of your faculty advisor.

III. Keep what is learned from or about Respondents confidential.

Everyone working on this project must maintain confidentiality. All information obtained during the interview that concerns Respondents or their families is privileged information. You should never talk about a Respondent's answers or use her name. Information should not be

shared with your family, friends, or other Respondents. The information may only be shared with the project personnel. We expect all interviewers to follow this rule.

IV. Be attentive to your appearance.

Your appearance is important to a successful interview. Try to dress in the middle range between very formal and very informal. We want you to be comfortable, but we also want Respondents to feel comfortable around you. Dressing too formally (i.e. business suits, etc.) may be considered inappropriate by some Respondents. Dressing too informally (i.e. torn or stained clothing, old or faded sweat pants, T-shirts, etc.) may offend others or cause them to doubt your professionalism.

Also be advised that certain personal habits such as smoking and gum chewing may turn Respondents off. Do not engage in such activities once you arrive at a Respondent's home.

V. Put the Respondent at ease so that she will feel free to answer personal questions.

The best way to do this is to be relaxed. Show a compassionate attitude and an interest in the Respondent's answers.

Although it is your responsibility to listen attentively, you should always maintain a certain degree of personal distance. For example, if the Respondent shifts the conversation to topics not relevant to the interview, direct her back to the interview schedule.

VI. Personal safety should always be considered.

Some suggestions for maintaining your personal safety include:

- Try to schedule interviews during daylight hours. If you must schedule one at night, ask the Respondent to leave a light on for you.

- Do not go into any situation where you feel uncomfortable. As an example, if a threatening dog is present, or if other people in the home seem threatening, leave and telephone the Respondent, as soon as possible, to reschedule your appointment.

- Do not be afraid to terminate an interview if you feel threatened. Do not jeopardize your safety under any circumstances.

INTERVIEW PROCEDURES

How were women selected?

Twenty women were selected in your county who have had breast cancer and who are African American and over 40 years old.

How to contact the women on your interview schedules?

Two persons who live and work in the county(ies) to which you are assigned will work with this project as Lay Health Workers. The role of these lay health workers is to recruit women to participate in this study. They are your liaison persons with the women you will be assigned to interview and will provide a list of names of women they have contacted who have agreed to be interviewed. Once you have received the names of the women you are to interview, you need to contact them to set up appointments for the interviews. If there is no phone number listed, you must reach them by direct contact. Your supervisor can help you make these contacts. This visit can be to set up an appointment or you can try to conduct the interview at that time.

Planning rules:

- 1- Interview only the women whose names are given to you. Never interview someone whose name is not given to you.
- 2- Plan your trips so that you can interview more than one person in the area, if at all possible. Schedule plenty of time between appointments.
- 3- Be punctual and avoid changing appointment times. If a woman is not home or breaks an appointment, contact her as soon as possible to reschedule. If **you** have to change an appointment, apologize to the Respondent and reschedule the appointment at **her** earliest convenience.

- 4- All interviews must be conducted in person. It is not acceptable to interview someone over the telephone. If A Respondent asks you to do the interview over the phone, tell her that you need to do it in person because you must show her certain parts of the interview.

MATERIALS TO BRING TO EACH INTERVIEW:

Interview Booklet

Pile Sort Cards

Tape Recorder, Tapes, and Extra Batteries

Extra paper

Pencils

Letter from your professor

College ID card

Name tag to be worn on your clothing.

HOW TO RESPOND TO RESPONDENTS' REFUSALS

Respondent: "I don't have time to do this now."

You: "It should only take about 1 hour to 1 ½ hours to complete the interview. I'm very flexible and we can do it at any time that is good for you."

Respondent: "I'm really not interested."

You: "It is very important that we interview everyone whose name was picked so we have a good understanding of what women think in your area. If we don't talk to everyone, the results won't be very helpful. So if you would please reconsider, I would greatly appreciate it."

Respondent: "I don't like studies like these."

You: "We understand that many people don't like to be asked a lot of personal questions, but this study is very important to help us learn some things that can hopefully improve the health of all women in this state. That's why we are talking to many women in the county."

Respondent: "My health is no one else's business."

You: "I can certainly understand if you feel this way. If you decide to speak to us, you are being generous with your time. All our interviews are confidential, and your name will not be put with answers you give. Protecting people's privacy is

one of our major concerns. You may skip any questions you want to.”

Respondent: “I don’t think I know enough to try to answer these questions.”

You: “These questions are not hard and there are no right or wrong answers. The questions ask for your opinions about certain things like your health and what you do to keep healthy. Some of the women interviewed were concerned at first but were at ease after we got started with the questions.”

CONDUCTING THE INTERVIEW

- 1. Introduce yourself:** My name is _____ and I am from _____
(Show a letter or ID card with the phone number.)
- 2. Remind the Respondent that she had been contacted before.**
- 3. Thank her for agreeing to participate** in the project and ask her if she has any questions before you start the interview.
- 4. Put the Respondent at ease.** Show genuine interest and be relaxed and friendly. Your sincerity and interest in the Respondent's feelings and family will help establish empathy.
- 5. Keep your introductory remarks brief.** Try to avoid excessive conversing and do the interview as soon as possible. Be courteous and let her know you can talk after the interview is over.
- 6. Try to interview the respondent alone.** Ask if there is a place the two of you can go so you will not be interrupted. Let her know the interview will go much faster if there are no interruptions.
- 7. Your lay advisor must get the Respondent's informed consent to participate in the project before you can interview the respondent.**
Make sure that this form has been signed before you start the interview.
- 8. Stress that there are no right or wrong answers and that her opinions are very valuable to the researchers and to other women like herself.**
Remind her that she was chosen along with the other women to let us know about their health care experiences and beliefs.

QUESTIONS OFTEN ASKED

Respondent: "What is this study about?"

You: "This interview is part of a study on breast cancer among African American women being conducted by Morehouse School of Medicine. We are doing this study to learn more about health care practices and beliefs of women in this county".

Respondent: "Is this private?"

You: " We are very concerned about confidentiality and protecting your privacy. Your name will not be mentioned to anyone and all the results are written up in a way that does not identify any individual. Your answers will never be put together with your name".

Respondent: "What kind of questions do I have to answer?"

You: "The questions are mostly about women's experiences with breast cancer. I'll be asking you about the experiences you have had, things you did before and after you were diagnosed with breast cancer. These are really easy questions and there are no right or wrong answers. We are very interested in your opinion and the opinions of other women like you".

HOW TO ASK INTERVIEW QUESTIONS

There are two types of questions that will be used in the questionnaire: **closed-ended** and **open-ended**.

Closed-ended questions are questions that have response categories on the interview you fill in. Closed ended questions can end with a question mark (?) or a colon (:). Here are examples of each:

Example: Do you currently do breast self exams?
 ___ YES ___ NO
 If no, why?

For closed-ended question, always read the question and all of the possible answers. After this, fill in the blank with the answer given by the Respondent. Several of the closed ended questions are followed by an open ended question. Write down the reasons given by the Respondent for answering either yes, or no, depending on the questions.

Open-ended questions just have a line for you to write in the answers. Some of these questions will have boxes for you to fill in the answers.

Example: How does your faith help you understand your experience with breast cancer?

Write down the Respondent's exact words. Begin writing as soon as the Respondent begins speaking. It may be helpful to repeat what was said to make sure you write every word.

Things to be careful about when asking questions:

- Use a pleasant tone of voice. Show interest in what the Respondent is saying, be confident, and have a professional manner.
- Make eye contact to show you're interested. Don't do things that indicate you might be judging the Respondent, like raising your eyebrows or frowning.
- Read questions slowly, about 2 words per second.
- Read each question exactly as it is written. ADD nothing except to probe.
- Don't forget to read transition statements that begin a section. These statements help set the tone for the questions that follow.
- Don't read out loud our instructions to you. These instructions will be labeled {**PROBE**} and are in **boldface print**.
- Don't skip questions unless you are instructed to do so. If the respondent answer the question in the narrative, then you can skip the designated questions. Some of the questions may be redundant but you are not instructed to skip. If the Respondent has already given you information that answers the question, you can comment: "I know we've talked about this..." or "I know you just mentioned this but I need to ask every question as it is written in the interview schedule.

To get accurate information from Respondents, it is important that you ask all questions in a uniform manner. That is, ask all Respondents the same questions in the same way and in the same order.

If a Respondent doesn't understand the question, don't try to explain to her what you think the question means. Instead, use one of the following methods:

- Repeat the entire question. Use this technique if you think the Respondent didn't hear the question.
- Repeat part of the question. Use this technique when the Respondent is unsure of what you are asking.
- Use the Vocabulary List at the end of the manual to give the definitions of some of the technical words. Take the Vocabulary List to each interview to ensure consistency.

Giving different explanations, synonyms, or clarifications to different Respondents means the questions are not being asked in a uniform or standard manner. This also means the questions won't be the same questions for all Respondents. When this happens, we can't be sure the answers are what the women really think or believe.

Recording Answers

All of the answers to the questions should be written down verbatim, if at all possible. Their words are important. Write down as much as you can in the words they use to answer the question.

Guidelines for recording answers:

- * Always use a pencil to record your answers.
- * Write legibly. You will be typing your answers into a computer program. The interview schedule will also be turned in and checked against the computer. Being able to understand your writing is very important.
- * Give the respondent as much time as they need to answer the questions and write down as much as you can.
- * You can use the back of the interview schedule if there is not enough room for the respondents answer.
- * Tape record the interview. Recorders and tapes will be provided for you at your supervisors office. **Be sure to label the tapes after you have recorded the interview.**
- *Take extra paper in case you need to make personal notes or messages.**

FEEDBACK

You can provide feedback to reward the Respondent for giving thoughtful answers.

- * Give short feedback for short responses like:

"I see....."

"Uh-huh"

"Thank you"

"Thanks"

- * Give longer feedback when the Respondent gives longer or more complicated answers:

"That's useful/helpful information"

"It's useful to get your ideas on this"

"It's important to get your opinion on this, thank you"

"I see; that's helpful to know"

"It's important to find out what women think about this"

- * Pause before giving feedback. Your pause signals the Respondent that you have considered her answer carefully.
- * Don't give feedback if the Respondent goes off track or doesn't answer the question.

Feedback should not be judgmental or show support for one answer over another. For example, don't say, "I agree with you on that" or "That's very good". This could bias the women to give answers she feels you will be pleased with.

PROBING

Probing is a method that is utilized by interviewers in order to clarify and/or expand a respondent's free response. Probes are used when a respondent's answers are unclear or she has not answered the question completely. Probing helps to clarify the Respondent's answers or to focus the Respondent on the specific content of the question and answer. They also aid in expanding the respondent's answer. Probes are very important to use for open ended questions.

Some examples of neutral probes are:

- * Pause for a while. A pause gives the Respondent time to be more thoughtful when answering.
- * Repeat the question or part of the question. This involves simply repeating the response choices. Repetition is used if the Respondent does not seem to understand the question or needs more time to think.
- * Ask clarifying questions.
 - "What do you mean?"
 - "Would you tell me more about your thinking on that?"
 - "What do you think?" or "What do you expect?"
 - "What do you believe about that?"
- * Pauses and repetition of the question are the best neutral probes to use when appropriate.
- * Adding the word "else" or "other" to the original question may obtain more or additional information.

For example:

Question

Probe

"Tell me about any home remedies" "What **other** remedies do you know about"

And/Or

"What **else** do (did) you take"

*Clarifying Probe Questions can obtain specific information if answers are ambiguous or vague. Anything not specific should be clarified. Frequently when the respondents make judgements in their answer, it is ambiguous or vague. Probing questions can be used to clarify their answers.

Example:

Question

Probe

"The doctor was good to me"

"How was the doctor good to you"

Probe questions are typed on the right margin of the interview schedule. Familiarize yourself with these questions before the interview. They are there to remind you to probe for unclear, incomplete, ambiguous, and vague answers. These questions are asked in **conversation** with the respondent. Try to write down everything the respondent says. Recording the interview is very important since it is sometimes *impossible* to write everything down.

NARRATIVES

A narrative is a story the respondents tells about her experiences with breast cancer. The first question on the interview schedule asks for a narrative. There are other questions that also ask for the respondent to answer the question in their own words telling you what they think is important. Each narrative questions have Probes to remind you do make sure that the respondent includes specific topics in their story. Asking the respondent a question in narrative form is like having a conversation about the topic of the question.

For example, question 1 has several probes that direct the interviewer to make sure that the respondent includes in your conversation their beliefs about what caused their illness, what kind of support they had during their illness, what were their symptoms, etc. **It is important that you probe in your conversation to make sure that the respondent gives you a detailed account of their experience.**

EDITING

Editing means rechecking the interview schedule after the interview, and out of sight of the Respondent, to be sure it is complete. Editing should be done as soon as possible after you have finished the interview.

- Make sure you fill in all the items on the cover page and the back page. Be sure to include your interviewer number, date of the interview, and the Respondent's information.
- Review the interview to be sure that every question that should be answered has a response. It is a good idea to check this before leaving the Respondent's home or while you are in the car before you leave the area. If anything is missing, it is likely that you will have to contact the Respondent again to get the information.
- Make sure the answers are written legibly. Fill in any words where you may have used shorthand during the interview.
- Be sure to write your comments in the space provided on the last page.

FREELISTING AND PILE SORTS

Freelisting is a research technique that asks respondents to make a list of all the items they can think of on a particular topic. For example, on the interview schedule, they are asked to list all the things they can think of that cause breast cancer. Let the respondents list as many items that they can. They can write them down or you can write them down for them.

Pile Sorts are a research technique that asks respondents to make piles of cards with words written on them. You have 20 cards for "cause", 18 cards for "symptom" and 14 cards for "treatment." Have the respondent make pile for each of these topics **separately**. You ask them to make as many piles as they want to of the items that are most like each other. The items in each pile should be more similar than the items in other piles. The number of piles will vary by respondent.

After the respondents have made their piles, ask the respondent why they put these items together. Record their answers on the sheet in the interview schedule. Then, record the number of each card under a pile number on the sheet in the interview schedule.

- In summary:
- (1) ask each respondent to make piles of the items on the cards they think are most similar
 - (2) ask each respondent why they put these items together (their reason for each pile)
 - (3) record their reasons on the sheet beside Pile 1, Pile 2, etc. **under "Reasons."**
 - (4) record the number on each card in each pile under pile 1, pile 2, pile 3, etc.

INTERVIEWER VOCABULARY

MAMMOGRAM: A picture of the breast tissue made by compressing the breast while the picture, a type of x-ray, is taken

MAMMOGRAPHY: The use of a mammogram to detect breast cancer

BIOPSY: The surgical removal of part of the lump to be sent to the laboratory to determine if it is cancer.

CYSTS: A fluid-filled sac or cavity that often enlarges and becomes tender and painful, but is benign.

BENIGN: Without cancer.

MALIGNANT: Cancerous.

LUMPECTOMY: The surgical removal of the cancerous lump and surrounding tissues.

MASTECTOMY: The surgical removal of the breast where cancer is found.

HORMONE REPLACEMENT THERAPY: Hormone-containing medicines that offset the symptoms of hormone loss during menopause.

FIBROCYSTIC DISEASE: Breast irregularities or lumpiness that are not cancerous.

EXPLANATORY MODEL: The cultural belief system concerning the manifestations and types of, causes of, possible treatments for, and other pertinent knowledge of an illness.

BREAST HEALTH BELIEF SYSTEMS STUDY
Personal Information Questionnaire

Subject ID: _____
Interview Date: _____
Last Name, First Name of Subject: _____
Mailing Address: _____
Street Address (if different): _____

General Information

1. What is your age? _____
2. Do you have any children? _____ Yes _____ No

2a. If yes, how many? _____
3. How much schooling have you completed?
_____ Less than 6 years _____ 7-9 years _____ 10 -12 years
_____ 1-2 years of college _____ Completed college
4. Are you: _____ Single, never married _____ Married _____ Separated
 _____ Divorced _____ Widowed _____ Live with partner

If married, for how many years? _____
If you live with your partner, how many years? _____
5. Who lives with you now?
_____ No one, I live alone.
_____ Husband/male companion _____ Brother(s)
_____ Mother/stepmother _____ Son(s)
_____ Father/stepfather _____ Daughter(s)
_____ Sister(s) _____ Other(s)
6. Including yourself, how many people live in your household? _____
7. How many years have you lived in this community? _____
8. Have you ever lived anywhere other than Georgia? _____ No _____ Yes

If yes, where did you live the longest?(City, State) _____
For how many years? _____

9. Do you attend church? ____ Yes ____ No

If yes, where do you go to church? _____

If yes, what church activities do you participate in?

____ Choir ____ Prayer meetings ____ Prayer groups
____ Support group ____ Sunday school ____ Other (Please describe) _____

10. At this time are you: ____ working for pay full time
____ working for pay part-time
____ self-employed
____ not working for pay

11. Are you: ____ retired from paid employment
____ laid off from a job temporarily
____ unemployed with disability
____ unemployed with out disability
____ a homemaker
____ Other(Describe) _____

12. What is/was your job called? _____

13. What is your yearly income? (Include your total family income from all sources and all the people that live with you.)

____ Under \$10,000 ____ \$20,000 - \$30,000 ____ don't know
____ between \$10,000 and \$20,000 ____ above \$30,000

14. Do you have a telephone? ____ Yes ____ No

If yes, What is the number? _____

If no, is there a number where you can be reached? _____

Health Care Information

15. Where do you regularly go for medical care?

____ Private doctor ____ A public clinic ____ The emergency room
____ Friends/neighbors ____ Other ____ No regular source of medical care

16. What do you use to pay for you medical expenses.(Check all that apply)

____ Personal income ____ Medicare ____ The VA

____ Family assistance ____ Medicaid ____ SSI

____ Medical Insurance ____ Don't Know

____ Don't have any type of health insurance

17. If you have medical insurance how much do you pay? _____

18. When were you diagnosed with breast cancer? (year/month)_____

19. Who told you?

20. How many times have you been pregnant?_____

21. Do you still get your period? ____ Yes ____ No

If yes, do you use any kind of birth control methods?

If yes, what kind? _____

22. Do you drink alcohol beverages? ____ Yes ____ No

If yes, how often?

____ 1-2 drinks per week ____ 3-4 drinks per week ____ 5 or more per week

23. How often do you eat fried foods?

____ 1-2 times a week ____ 3-4 times per week ____ 5 or more times per week

____ once a month ____ none

24. How many servings of fruit and vegetables do you eat each day?

____ one ____ two ____ three ____ four

____ five ____ six ____ none ____ other

25. How many servings of meat do you eat each day?

____ one ____ two ____ three ____ four

____ five ____ six ____ none ____ other

26. How often do you exercise?

____ 1-2 times per week ____ 3-4 times per week ____ 5-7 times per week

____ once a month ____ I don't exercise

27. Have you had a hysterectomy? ____ Yes ____ No

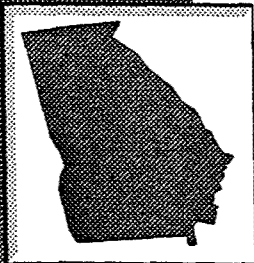
28. Do you take hormone pills? ____ Yes ____ No

29. Other than breast cancer, have you had any other kind of cancer? ____ Yes ____ No
If yes, what kind(s)? _____

30. Do you have any relatives who have had cancer? ____ Yes ____ No

If yes, who had cancer and what kind of cancer did they have?

Thank you very much for your assistance.



Breast Health Belief Systems Study

Morehouse School of Medicine

Contents

**Interview Schedule
Observations
Free Listing and Pile Sorts
Observations**

Respondant _____

PROBES

Use back of this page if needed.

ID# _____

PROBES

2. How did you know something was wrong with your breast?

Skip if in narrative

**Symptoms
Context**

3. Who did you talk to first?

Skip if in narrative

**Reasons for
choosing
person.**

**Details of
what they
talked about**

4. What did your family, friends and minister say and how did they act towards you?

Behavior

Stigma

Advice

5. How long was it until you saw a doctor?

Less than a week _____
1 - 2 weeks _____
3 - 4 weeks _____
1 - 3 months _____

4 - 6 months _____
7 - 9 months _____
10 - 12 months _____
Over one year _____

5a. Why did you wait?

If over two weeks.

6. Did you ever think you would get breast cancer? ____ Yes ____ No

Explain.

Why?

7. Why do you think some women get breast cancer and some women don't?

ID# _____

PROBES

8. What do you think caused your breast cancer?

9. What did the doctor prescribe for your treatment of breast cancer?

10. Have you completed this treatment? ____ Yes ____ No
If no, why not?

11. Prior to your diagnosis of breast cancer did you go to the doctor on a regular basis?
____ Yes ____ No. Why or why not?
Skip if in narrative

12. Do you go to the doctor on a regular basis now? ____ Yes ____ No
Why or why not?

13. What kind of doctor do you prefer?
White ____ male ____ doesn't matter ____
Black ____ female ____ other ____

14. How do you feel about your doctor(s) in general?

**Detail both
good & bad
experiences**

**Type of
doctor**

Race

Gender

ID# _____

PROBES

15. Did you have a mammography prior to your diagnosis of breast cancer?

☒ Yes ☐ No

15a. If yes, when was the first one?

Tell me about these experiences?

15b. If no, why not?

16. Did you ever do self breast exams prior to your diagnosis of breast cancer?

☒ Yes ☐ No

16a. If yes, how often and how did you know how to do a breast self exam?

16b. If no, why not?

17. How did you feel about touching your breasts?

18. Do you currently do breast self exams? ☒ Yes ☐ No

18a. If no, why?

19. Do you currently get mammographies as a part of your health care?

☐ Yes ☐ No

20. Do you currently get clinical breast exams as a part of your health care?

☐ Yes ☐ No

PROBES

_____ Yes _____ No

22a. Do you agree with that idea ? Yes No

Explain.

Drugstore

Teas

Roots

Herbs

This image shows a single sheet of white paper with horizontal blue or grey ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

Beliefs

Healing

Surviving

Minister

Church

Groups

God

Scripture

Sermons

ID# _____

PROBES

33. What people/groups/organizations have helped you with breast cancer?

_____	Names

_____	Locations

_____	Services offered

34. We are interested in finding out the ways you get information about breast cancer.

I will read a list of information sources and ask you to tell me whether you receive information about breast cancer from the sources below before you had breast cancer.

	Yes	No
a. Daily Newspaper		
b. Through the mail		
c. At senior centers		
d. At my club meetings		
e. At my church		
f. From close friends		
g. From family members		
h. People in the community with healing powers		
i. From t.v.		
j. From radio		
k. The pharmacist		
l. Grocery store magazines and other reading materials		
m. From booklets, pamphlets		
n. From my doctors		

35. Of the information sources above, which ones do you trust the most?

ID# _____

36. We are interested in asking you some specific questions about your faith. Please tell me if you agree or disagree with each statement:

	Agree	Disagree	Undecided
God would work through the doctors and nurse to cure cancer.			
You would trust more in God to cure your cancer than medical treatment.			
You would refuse medical treatment and trust only in God to cure cancer.			
Only a religious miracle treatment could cure your cancer, not medical treatment.			
Your cancer would be because you had sinned against God.			
It would be your responsibility to pray every day that God would cure your cancer.			
The strength of your own faith in God would determine if your cancer was cured.			
Your prayer alone would do nothing to cure your cancer.			
You would want your church members to come to the hospital to pray with you.			
Your church members praying in church would help to cure your cancer.			
There would be a special ceremony for you in your church to cure your cancer.			
You would not tell anyone in your church about your cancer.			
You would not ask people in church to pray for you.			

ID# _____

OBSERVATIONS

ID# _____

FREE LISTING

The final questions in this interview are listing questions. I am going to ask you to list all the words or phrases that you can think of for the symptoms, causes and treatments of breast cancer:

First, list all the symp/oms of breast cancer that you know:

_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Second, list all the causes of breast cancer that you know:

_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Third, list all the treatments of breast cancer that you know:

_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

PILE SORTS

I am going to give you a set of cards. Please look at the words and phrases on these cards and make piles of the words and phrases that are most alike. You can make as many piles as you wish. After you make the piles, I will ask you why you put the words and phrases in each pile together.

ID# _____

SYMPTOMS

Pile 1

Pile 2

Pile 3

Pile 4

Pile 5

Pile 6

Pile 7

REASONS

Pile 1:

Pile 2:

Pile 3:

Pile 4:

Pile 5:

Pile 6:

Pile 7:

ID# _____

CAUSES

Pile 1

Pile 2

Pile 3

Pile 4

Pile 5

Pile 6

Pile 7

REASONS

Pile 1:

Pile 2:

Pile 3:

Pile 4:

Pile 5:

Pile 6:

Pile 7:

ID# _____

OBSERVATIONS

ID# _____

TREATMENTS

Pile 1

Pile 2

Pile 3

Pile 4

Pile 5

Pile 6

Pile 7

REASONS

Pile 1:

Pile 2:

Pile 3:

Pile 4:

Pile 5:

Pile 6:

Pile 7:

Breast Health Belief Systems Study

PHASE THREE:

Health Education Intervention

Morehouse School of Medicine
Gerontology Center
Department of Community Health & Preventive Medicine
Atlanta, Georgia

THE BREAST HEALTH BELIEF SYSTEMS STUDY

IMPLEMENTATION PROCUDURES

The Breast Health Belief Systems Study is a research Study that will provide breast health information to women living in rural communities. The Study will take place three different rural communities.

1. Preparing to Begin

- ☐ Organize your notebook so that you have a written record of your time, extra mileage, and out-of-pocket expenses.
- ☐ Document at least one (preferably 2-3) clinical sites that offer low- or no-cost mammograms in your area.

2. Logs & Documentation

- ☐ In a research study, all aspects of the work **MUST** be carefully documented. For this reason, be sure to carefully document all of your activities in your Study notebook, so that all information will be centralized in one place. It is important to keep the notebook in your possession or put away, and not laying out for other people to look at.
- ☐ Things that are important to document are:

Contact/call-back information for study participants
All out-of-pocket expenses incurred while doing Study work.

Quality Control

In order to verify the correct recording of information, the Project Coordinators will ask to see your notebook from time to time.

A member of the Study Team will randomly select participants' completed Contact Forms and Personal Information Questionnaire (PIQ) from each Study site, and verify participation and eligibility criteria via telephone. The results of these verifications will be reported to the appropriate Interviewer.

3. Selection Criteria and Recruitment Efforts

All participants in the Study **MUST** meet **ALL** the following criteria:

- African American female aged 40 or older
- No mammogram within the preceding 12 months
- No history of breast cancer or breast surgery

WHERE, WHEN, HOW MANY

Review your roster of the families you know and have regular contact with. Eliminate those families that do not include at least one woman 40+ years old. The rest will make up your **PROSPECT LIST** (those families that have one or more women 40 years old or older). You may need to update your **PROSPECT LIST** as the work progresses because you will need to complete at least a total of 100 surveys--50 in Group A and 50 in Group B.

4. Making Contact with Participants

Contact the families on your **PROSPECT LIST**, explain the Study, and ask if there are one or more women in the household 40 years old or older who would like to participate. Be sure to mention that women who meet the selection criteria and agree to participate will be paid \$10. Determine whether each woman who wishes to participate satisfies **ALL** of the selection criteria.

To help in recruiting study participants, you may ask the women on your **PROSPECT LIST** to suggest friends and acquaintances living nearby.

When explaining the Study, say something like:

"The Belief Systems Study is looking at what people think about breast health and breast disease prevention including getting a mammogram. All participants will complete two short surveys and receive an information packet about getting a mammogram. Some participants will also have a few brief conversations with me about breast health and getting a mammogram. All women who participate will receive \$10.00."

VERY IMPORTANT

Record the names, addresses and phone numbers of those women who successfully satisfy the selection criteria and agree to be enrolled in the Study on the **CONTACT SHEETS**.

THINGS NOT TO DO

Don't tell anyone else what any Study participant says when you are discussing breast health or breast disease.

Don't discuss the scientific basis of the research with anyone.

Don't minimize participation in the Study by beginning recruitment statements with, "All you have to do is..."

5. Scheduling Visits

After the first visit, return visits must be scheduled no sooner than 30 days apart.

6. Issues of Confidentiality

- ☐ Confidentiality in medical research studies is very important. Each Interviewer will be responsible that all safeguards to data confidentiality are maintained. The Project Coordinators will monitor compliance to ensure high levels of confidentiality.
- ☐ Participation in the Study, filling out some surveys, and talking about breast health may not seem very important in terms of confidentiality. It is essential to bear in mind that what may seem to be unimportant to you, may be very important to others.
- ☐ You will have no way of knowing if a participant is struggling with breast cancer fears, whether breast cancer has touched close friends or other members of her family, or whether a participant has found a lump but is fearful of consulting a health care provider. Therefore, maintain a professional and courteous manner at all times.
- ☐ Never discuss your Study activities with anyone who could be a participant or who might know one or more potential participants. Participants must believe that confidentiality will be maintained.

- ❑ Two types of information are being collected: (1) personal information about age, income, health histories of the participant as well as of her family, and (2) attitude information about what the participant thinks about several things.
- ❑ In order to obtain reliable and truthful information, participants must believe that their responses to questions will be kept confidential.
- ❑ If the participant feels that the information she is providing may not be held in confidence, or might be gossiped about, or might somehow be shared with other people in the community, she is more likely to provide inaccurate information.
- ❑ Providing inaccurate or defective information is worse than providing no information at all.
- ❑ Never photocopy completed surveys.

Remember: Do NOT discuss anyone's participation in the Belief Systems Study, whether or not she is enrolled, or any parts of her conversations with you even if you think it won't matter or that the participant won't mind. If the participant chooses to disclose her participation to anyone, that is up to her.

7. Completing the Informed Consent Form

The Informed Consent Form should be completed *after* you have satisfied the eligibility criteria and the woman or women have agreed to participate.

Provide an Informed Consent Form before administering the Personal Information Questionnaire and any parts of the intervention. Give the participant time to read the consent form completely.

Tell the participants that the telephone number they provide may be used for the telephone follow-up. If a participant is called, interviewers will speak **ONLY** with the Study participant, and not to other family members or friends. Tell participants to indicate whether the phone number they provide is a day or an evening phone number.

Make sure that everyone completes the Informed Consent Form and signs it:

Printed Name & Signature
 Address
 City, State, Zip
 Phone Number

There is a place for you to sign the Informed Consent Form as a witness. Do this AFTER the participants have completed and signed the form. Give a copy of the Informed Consent Form and the Response Card to each participant.

8. Assigning the Study ID Number

You may be provided with a Randomization List containing approximately 100 Study ID Numbers, each assigned to either Group A or Group B. As you begin to recruit participants, be sure to begin at the top of the list. Don't skip any ID's. When an ID is assigned to a participant, cross it out so that you don't accidentally assigned that ID to another participant.

It is very important that the Study ID Number appear on all Study documents including:

- Contact Sheet
- Personal Information Questionnaire
- Response Card
- Survey One
- Survey Two

While the participant is reading the consent form, consult your Randomization List to obtain the Study ID Number and to determine if the participant is in Group A or Group B. Choose the appropriate Response Card and write the participant's Study ID Number on it (*no name, address, or phone number*).

LIBERTY	STEWART	TWIGG
AL00X	AS00X	AT00X
BL00X	BS00X	BT00X

If you visit a participant on a second or third occasion, code Survey One, Survey Two, and Response Card with a FINAL 2 or 3.

AL00X2	AS00X2	AT00X2
AL00X3	AS00X3	AT00X3

9. Providing the Response Card

The Response Cards are color-coded by site and by group. This means that each Interviewer will receive a quantity of TWO colors--one color is for participants assigned to Group A and one color is for participants assigned to Group B.

If you visit a participant a second or third time, give a new response card (with a revised code--see above).

10. Completing the Personal Information Questionnaire (PIQ)

After the informed consent form as been signed, and the participants has received her copy, complete the Personal Information Questionnaire.

Introduce the PIQ to each participant saying that the question involve personal information about her age, marital status, income ranges, mammography history, etc.

Say: "If you like, I can read each question and the answer choices, and check then off for you, or would you prefer to answer these questions yourself and check them off?"

Complete the PIQ in the way the participant wants to.

11. Completing the FIRST Survey

Before proceeding any further, complete the 6-question survey. Reiterate that all information will be held in confidence. Ask participants to respond to each question to the best of their ability. Don't discuss anything on the surveys or try to influence how a participant answers a question. Tell the participant to choose an answer **ONLY** from those given that **MOST CLOSELY** reflects her beliefs or attitudes.

12. Concluding the Initial Intake Process

Group A: If the participant has been assigned to Group A, give her the information packet, and continue with the intervention discussed below. Be sure that you have obtained the signed Informed Consent Form, and have given the participant the correct Response Card.

Group B: If the participant has been assigned to Group B, give her the information packet, and arrange a time when her participation can be concluded. (To make this easier, it is OK to arrange group meetings with several participants **from Group B ONLY**.) Be sure that you have obtained the signed Informed Consent Form, and have given the participant the correct Response Card. A second meeting will be required so that the participant has enough time to review the material in the information packet, and to complete the **SURVEY TWO**.

13. Presenting the Intervention (Group A ONLY)

The intervention is the brief conversation you will have with each Study participant in Group A. The content of the conversations must include each of the nine talking points in order. The presentation for each conversation will be left up to each Interviewer since she knows the women who will be participating in this Study.

If a participant appears to become uncomfortable, does not wish to continue the conversation, or attempts to change the subject, discontinue the intervention. Try to engage this participant again at a later date. If at that time, she demonstrates the same discomfort, then this woman's participation has ended, and she is not entitled to the \$10 participation incentive.

It is very important that you **THOROUGHLY** understand the talking points and are comfortable with this information. Do **NOT** provide extraneous information or personal opinion regarding any of the talking points.

14. Completing the SECOND Survey

For Group A: Immediately after you have covered the itemized talking points of the intervention, conduct the SECOND survey.

For Group B: Set up a second meeting with each participant in Group B. If more convenient, you may meet with several participants (in Group B) at one time. Before giving the SECOND SURVEY, inform participants that you **MAY NOT** discuss anything in the information packet, or any other issues relating to breast health, breast cancer, or getting a mammogram. Refer the women to a BreasTest & More local site or to the American Cancer Society 1-800 information source, or to one of the local mammography providers on the referral list.

For Both Groups: Give each participant the Response Card, and instruct her to take the card with her when she has her mammogram done. Explain that the provider should indicate that she has had a mammogram where indicated on the card. Tell the participant to drop the postage paid card in any mailbox. **Emphasize that no name or other identifying information will appear on the card.**

15. Presenting BSE Information (Group A ONLY)

Provide the participant with breast self-examination materials. Allow the participant several minutes to read, review, and discuss these materials. Using the breast model, demonstrate BSE. Ask the participant to palpate the breast model. Be sure to point out lumps and cysts.

16. Providing Referral Information (BOTH Groups)

Provide the participant with a copy of the list of referral sites for low- or no-cost mammograms including the name, address, and phone number of the facility, any pertinent appointment scheduling information, and if possible, driving directions. If the facility is low-cost, include information about payment.

17. Reiterating Follow-up Procedures

The follow-up is a key element. Stress the importance of this final step of the research study. If the participant decides to get a mammogram, it is very important that she use the postage-paid response card. No identifying information will appear on the card that may embarrass her. When she returns the response card, her involvement with the Study is over.

For women who decide *not* to get a mammogram or who do not return the response card, telephone interviewers will contact them. They will make every effort to call Study participants at convenient and appropriate times. This brief conversation should last no longer than about 10 minutes.

18. Providing the Incentive

Each participant (in BOTH Groups) will receive an incentive of \$10.00 to participate in the Study. Participation means that the woman has provided truthful information about her eligibility, completed the PIQ, and completed BOTH the FIRST and SECOND Surveys. This means that members of Group A will receive their incentive upon completion of the first encounter. Members of Group B, however, will receive their incentive after the second encounter when they complete the SECOND Survey. Participants who withdraw or decline to complete ALL of the necessary documentation, cannot receive the \$10.00 incentive.

For both groups, upon completion of the SECOND Survey and all other documents, give the participant \$10.00 in cash and have her sign the CASH RECEIPT FORM indicating that she has received the incentive payment. At the bottom on the sheet, there is also a place for you to sign indicating that you have provided the incentive money to the participants.

19. To Review:

Upon completion of the initial visit,

INTERVIEWER HAS

1. A completed one Contact Form
2. Collected the Informed Consent Form
3. Collected the PIQ
4. Collected the FIRST SURVEY (A & B)
local mammogram providers
5. Provided info packet & intervention (A only)
Provided info packet (B only)
6. Collected the SECOND SURVEY (A only)
7. Provided a list of no- or low-cost
local mammogram providers.
8. Provided the incentive (A only)

PARTICIPANT HAS

1. Received a copy of the Informed
Consent Form
2. Received Info packet
3. Received Response Card
4. Received list of no- or low-cost
5. Received incentive (A only)

Upon completion of 2nd or 3rd visit

GROUP A

1. Repeated the FIRST SURVEY
2. Repeated the INTERVENTION
3. Repeated the SECOND SURVEY
4. Provided a new Response Card

1. Received a new Response Card

GROUP B

1. Collected the SECOND SURVEY
2. Provided the incentive

1. Received incentive

Thank each participant for their cooperation.

BREAST HEALTH EDUCATION TALKING POINTS

1. Importance of preventive behavior (reinforcement); personal empowerment
2. Good health is a spiritual gift.
3. Evaluation of risk; nutrition; obesity; family history; smoking;
4. BSE, clinical exam, mammographic procedures
5. Fear of diagnosis, or of curative/surgical intervention.
6. Fear or discomfort with BSE (relating to auto-stimulation) or mammography
7. Issues relative to spouse and/or family support
8. Issues relative to expense; sources of funding, SSI information
9. How to talk to, listen, and understand the doctor. Taking a friend/spouse with them to doctor to understand MDs message

A

Dr. Mary Williams
Morehouse School of Medicine
720 Westview Dr., SW
Atlanta, GA 30310

B

Dr. Mary Williams
Morehouse School of Medicine
720 Westview Dr., SW
Atlanta, GA 30310

ID Number _____

RESPONSE CARD

As part of your participation in the Breast Health Belief Systems Study at Morehouse School of Medicine, Atlanta, GA, please give this card to your mammogram provider. Ask him/her to complete the information below.

Simply drop the card in the mail. It is postage-paid.

Please indicate the date and organization name below

Performed on (date) _____

By _____

For questions or concerns, contact Dr. Mary Williams, Morehouse School of Medicine, (404) 752-1626.

BREAST HEALTH BELIEF SYSTEMS STUDY

CONTACT FORM

Name _____ Phone _____ Alt. Phone _____

Address _____ City _____, CA Zip _____

ELIGIBILITY GUIDELINES

African American female aged 40 or older? Y N
 Ever had a mammogram? Y N
 If yes, about how many months/years ago? _____
 History of breast cancer? Y N
 History of breast surgery? Y N

☐ NOT ELIGIBLE

ID Number _____

CHECKLIST

- ☐ 1. Informed Consent signed
- ☐ 2. ID Number & Group assigned
- ☐ 3. Personal Information Questionnaire (PIQ)
- ☐ 4. Survey ONE completed
- ☐ 5. Provided info packet

GROUP A

- ☐ 6. Delivered INTERVENTION
- ☐ 7. Survey TWO completed
- ☐ 8. Provided Response Card
- ☐ 9. List of mammogram providers
- ☐ 10. Paid incentive
Got signed receipt
- ☐ 11. Repeated the Survey ONE
- ☐ 12. Repeated the INTERVENTION
- ☐ 13. Repeated the Survey TWO
- ☐ 14. Provided a new Response Card
- ☐ 15. Repeated the Survey ONE
- ☐ 16. Repeated the INTERVENTION
- ☐ 17. Repeated the Survey TWO
- ☐ 18. Provided a new Response Card

GROUP B

- ☐ 6. Scheduled Survey TWO
- ☐ 7. Completed Survey TWO
- ☐ 8. Provided Response Card
- ☐ 9. List of mammogram providers
- ☐ 10. Paid incentive
Got signed receipt

 Signature of Interviewer

ID # _____

BREAST HEALTH BELIEF SYSTEMS STUDY**SURVEY ONE**

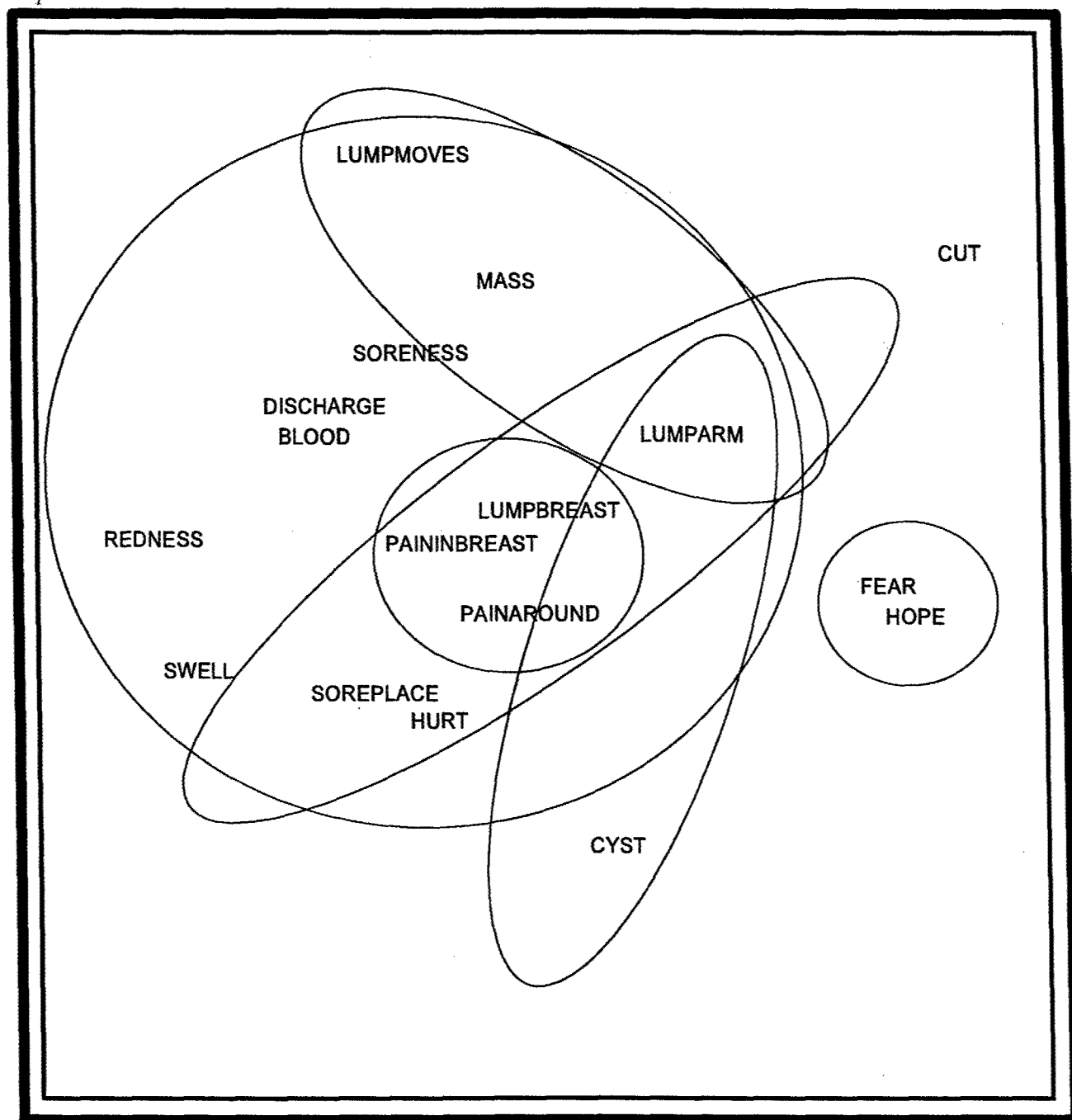
		Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1.	Breast cancer is a serious, possibly life threatening disease.	1	2	3	4	5
2.	It could happen to you.	1	2	3	4	5
3.	There are steps you can take to decrease your chances of getting breast cancer.	1	2	3	4	5
4.	Mammograms really work at finding breast cancer early.	1	2	3	4	5
5.	Monthly breast self-examination is important for maintaining breast health.	1	2	3	4	5
6.	No matter what you do, if you're going to get breast cancer, you're going to get it.	1	2	3	4	5
7.	Assuming that free or low-cost breast health services were available nearby, you would use them.	1	2	3	4	5

ID # _____

BREAST HEALTH BELIEF SYSTEMS STUDY

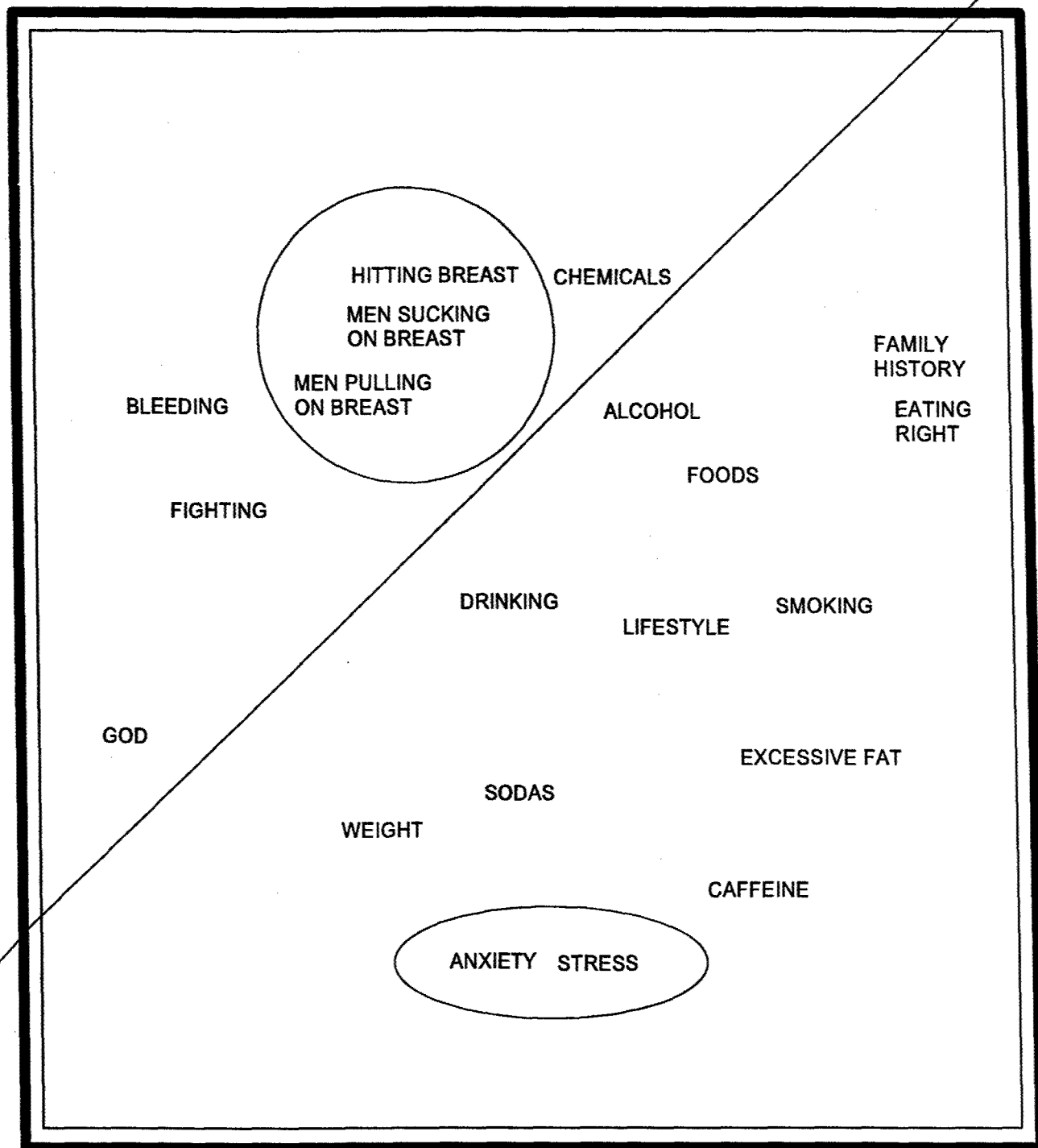
SURVEY TWO

		Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1.	Breast cancer is a serious, possibly life threatening disease.	1	2	3	4	5
2.	It could happen to you.	1	2	3	4	5
3.	There are steps you can take to decrease your chances of getting breast cancer.	1	2	3	4	5
4.	Breast self-examination and mammograms really work at finding breast cancer early.	1	2	3	4	5
5.	Monthly breast self-examination is important for maintaining breast health.	1	2	3	4	5
6.	No matter what you do, if you're going to get breast cancer, you're going to get it.	1	2	3	4	5
7.	Assuming that free or low-cost breast health services were available nearby, you would use them.	1	2	3	4	5
8.	Since our last conversation about breast health and breast cancer, have you obtained or attempted to obtain a clinical breast exam or a mammogram?	Y				N



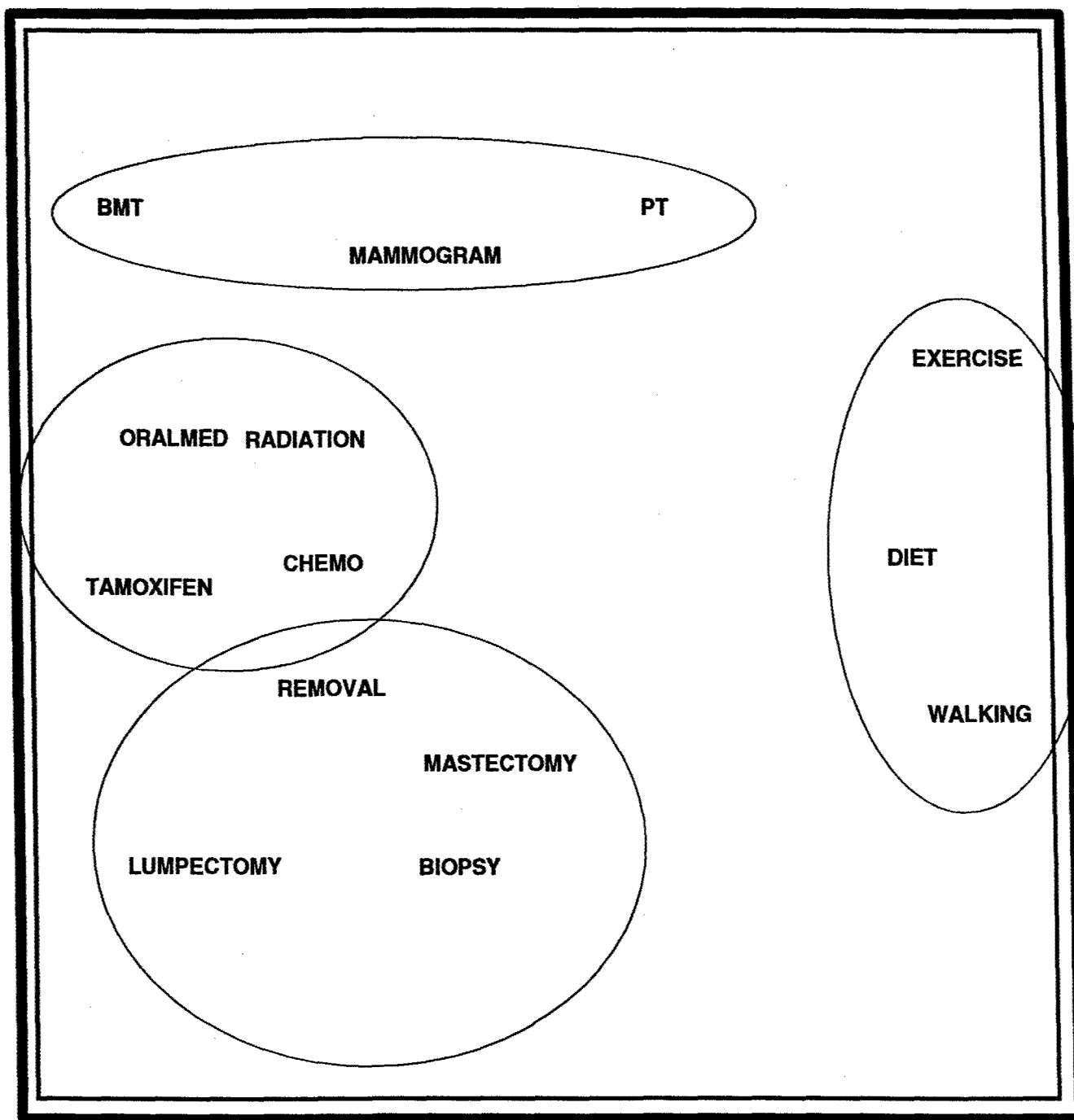
SAVANNAH - SYMPTOMS

ANTHROPAC 4.0



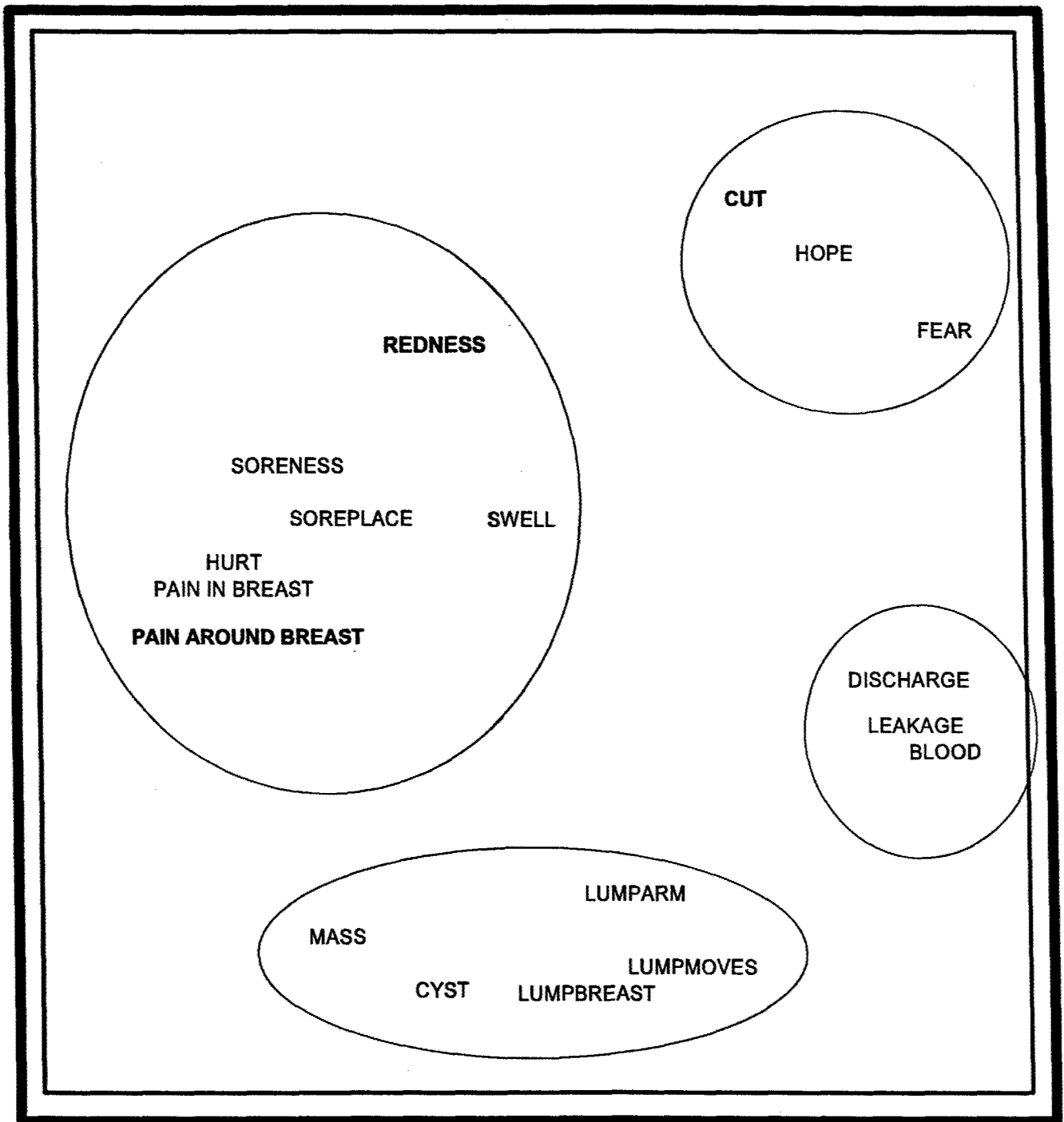
SAVANNAH - CAUSES

ANTHROPAC 4.0



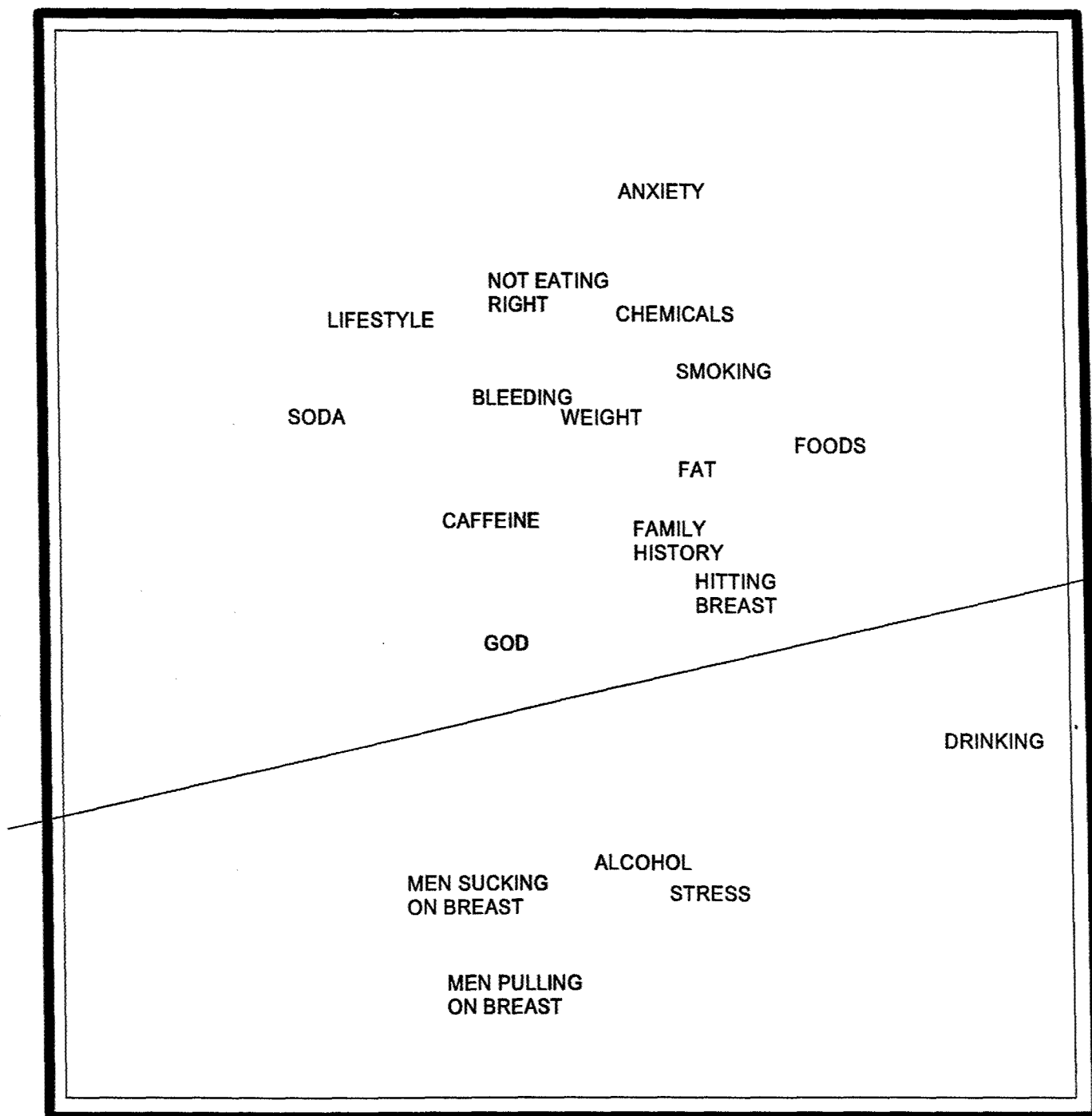
SAVANNAH - TREATMENTS

ANTHROPAC 4.0



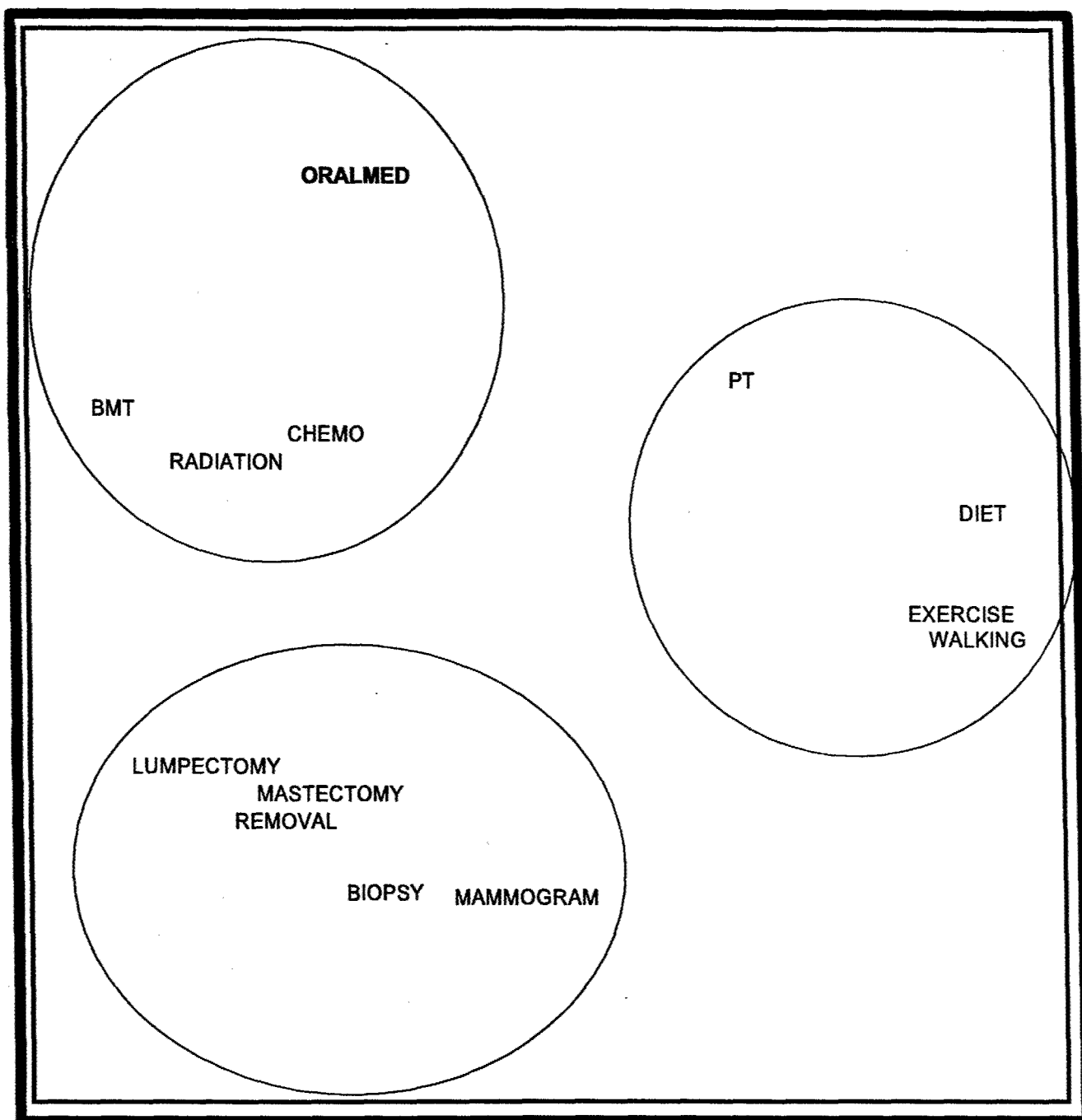
ALBANY - SYMPTOMS

ANTHROPAC 4.0



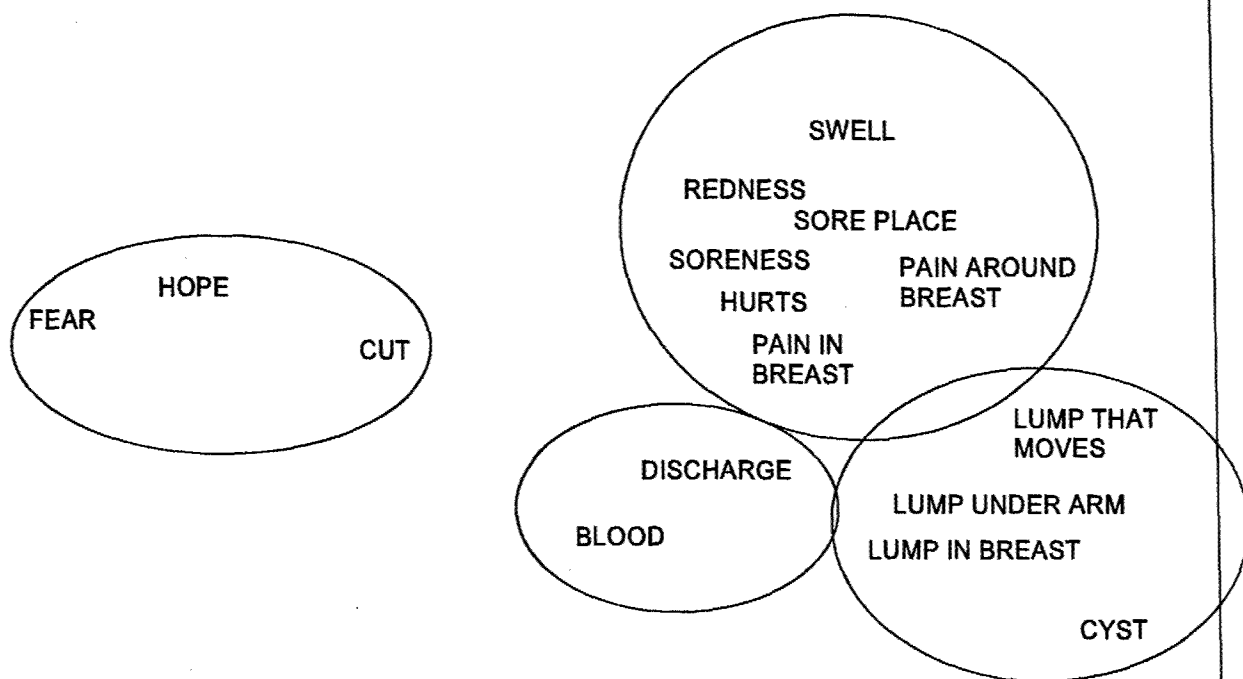
ALBANY - CAUSES

ANTHROPAC 4.0



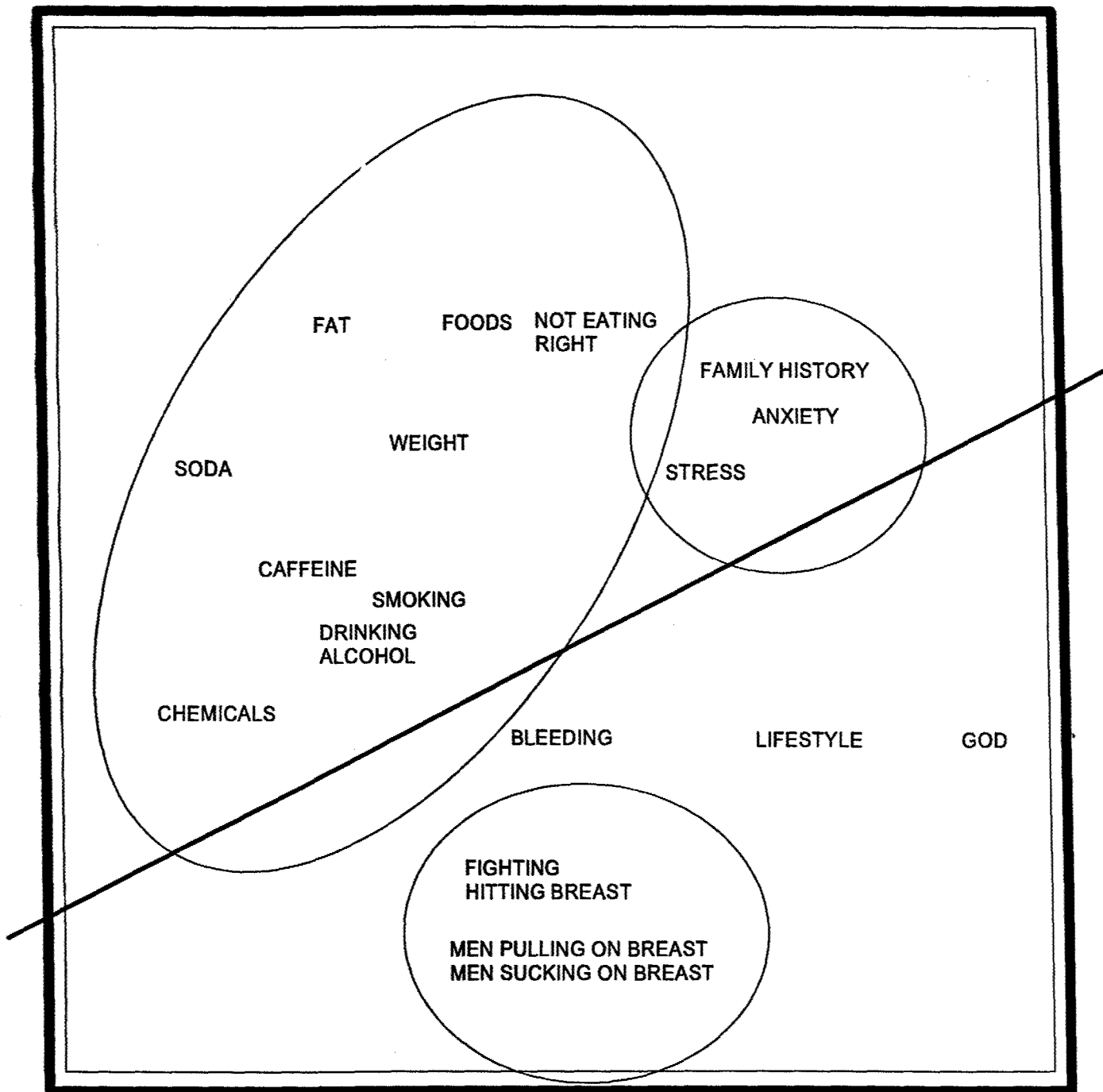
ALBANY - TREATMENTS

ANTHROPAC 4.0



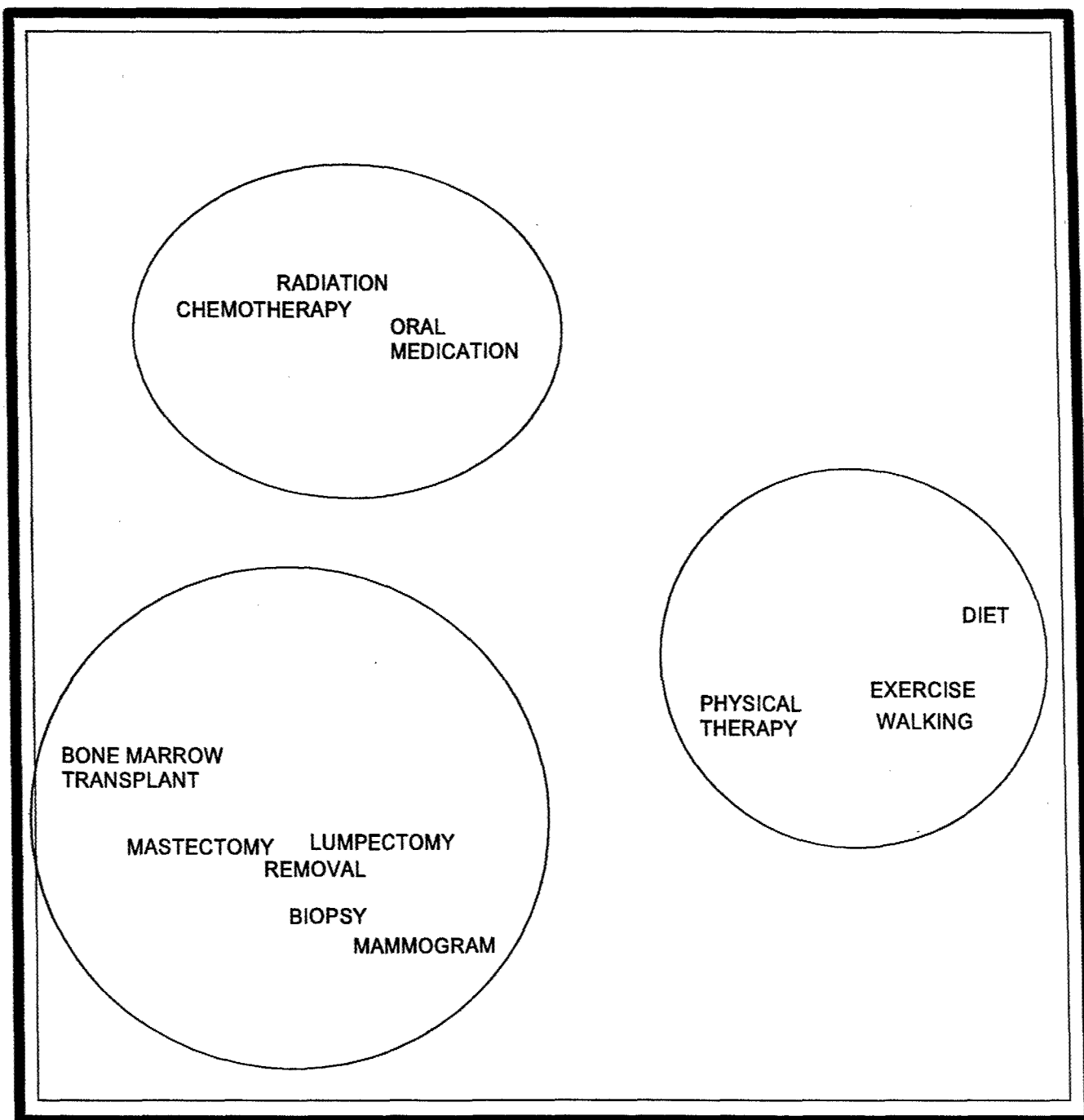
MACON - SYMPTOMS

ANTHROPAC 4.0



MACON - CAUSES

ANTHROPAC 4.0



MACON - TREATMENTS

ANTHROPAC 4.0



DEPARTMENT OF THE ARMY
US ARMY MEDICAL RESEARCH AND MATERIEL COMMAND
504 SCOTT STREET
FORT DETRICK, MD 21702-5012

REPLY TO
ATTENTION OF

MCMR-RMI-S (70-1y)

1 July 03

MEMORANDUM FOR Administrator, Defense Technical Information Center (DTIC-OCA), 8725 John J. Kingman Road, Fort Belvoir, VA 22060-6218

SUBJECT: Request Change in Distribution Statement

1. The U.S. Army Medical Research and Materiel Command has reexamined the need for the limitation assigned to technical reports written for this Command. Request the limited distribution statement for the enclosed accession numbers be changed to "Approved for public release; distribution unlimited." These reports should be released to the National Technical Information Service.

2. Point of contact for this request is Ms. Kristin Morrow at DSN 343-7327 or by e-mail at Kristin.Morrow@det.amedd.army.mil.

FOR THE COMMANDER:

Encl

PHYLLIS M. RINEHART
Deputy Chief of Staff for
Information Management

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